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2014

12th World Congress of Bioethics: Inspire the Future to Move the World

25-28 junio 2014

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12th World Congress of Bioethics

June 25-28 Mexico City 2014

BIOETHICS

INSPIRE THE FUTURE TO MOVE THE WORLD

CONBIOÉTICA
Comisión Nacional de Bioética
México

International Association of Bioethics

Under the slogan *Inspire the future to move the world*, the National Commission of Bioethics of Mexico (CONBIOETICA) organized, from June 25nd to 28th, the 12th World Congress of Bioethics, which gathered the world-renowned experts, researchers and scholars in the field. This event made it possible to address the leading tendencies in the field of Bioethics, their development and application, as well as to strengthen actions that may help to spread Bioethical knowledge in research, teaching and healthcare among experts and the general population. The themes addressed in the congress were grouped into four main categories: Global Health, Science, Society, and the Individual.

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First edition 2015

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C.P. 14610, Deleg. Tlalpan, México, D.F.
Phone: +52 55 54872760
http://conbioetica-mexico.salud.gob.mx
ISBN: 978-607-460-475-7

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Design: EDITARTE
www.editarte.com.mx

Printed and made in Mexico

Editor's note:

The views expressed on this publication are those of the authors and do not necessarily reflect the point of view of the National Bioethics Commission of Mexico. All images and pictures were taken from the authors' presentations.

It was considered best to keep the original sense of the plenary sessions´ lectures. Consequently, these are published in the language they were delivered, which is also, why some of them appear in English or Spanish, and only a style review was made -barely correcting slip-ups in the spoken discourse.

CONTENT

PRESENTATION

Resulta muy grato para México haber albergado el 12° Congreso Mundial de Bioética y para la Secretaría de Salud de México reviste un gran honor y, al mismo tiempo, representa una especial oportunidad ser el anfitrión de este magno evento, en donde se han dado cita los más destacados especialistas, investigadores y estudiosos de la bioética de todo en el mundo.

En un contexto como el que caracteriza nuestro tiempo, lo local y lo global guardan una innegable correlación. El conocimiento científico y sus aplicaciones tecnológicas, principalmente en el terreno de la medicina y la salud, aunque en otros territorios del saber también ocurre, tienen una determinante influencia en todo espacio de vida y un impacto que se desborda también en lo económico, en lo político y en lo social en su más amplio sentido.

Es por ello que la realización del 12º Congreso Mundial de Bioética en la Ciudad de México, ha sido crucial para ensanchar el horizonte temático de la bioética, poner en la palestra su importancia individual y social, así como abrir cauces para actuar bajo principios que antepongan los fundamentos y conocimientos bioéticos.

El Congreso representó una oportunidad única para que la sociedad, los estudiosos del área y otros interesados se acerquen a la bioética por medio de uno de los eventos con la mayor tradición contemporánea en la materia en el contexto internacional.

La edición de este nuevo encuentro guarda un particular interés, pues se realiza de nuevo en el continente americano después demás de una década y, en particular, en un país latinoamericano como México, que ha desplegado un esfuerzo muy significativo por ir consolidando este campo de conocimiento en el país en diversos órdenes.

Entre varios de los propósitos que se cumplieron en esta edición, vale la pena destacar el contacto e intercambio de información entre

aquellos que trabajan en bioética en diferentes partes del mundo; organizar y promover conferencias de bioética internacionales periódicas; promover el desarrollo de la enseñanza e investigación en bioética y, por supuesto, defender el valor de un diálogo libre, abierto y razonado sobre temas de bioética.

El Congreso ha sido, sin duda, una gran oportunidad para dar a conocer los proyectos y avances en bioética que se han realizado durante los últimos años. Del mismo modo, permitió una amplia retroalimentación y deliberación incluyente que generará aportaciones importantes tanto para nuestro país como para la región de las Américas y el mundo en general. ◗

Mercedes Juan
Secretaria de Salud de México

FOREWORD

Under the slogan ***Inspire the future to move the world,*** the National Bioethics Commission of Mexico (CONBIOÉTICA) organized, from June 25th to 28th, the 12th World Congress of Bioethics; this event served to address leading trends in the field of bioethics, their development and application, as well as to strengthen actions that may help to spread Bioethical knowledge in research, teaching and healthcare among experts and the general population.

For these purposes more than 1,200 persons from 72 countries from 5 continents were convened. This achievement was based on the tireless labor of the National Bioethics Commission of Mexico (CONBIOÉTICA)

Bioethics is a field in which numerous professionals and experts engage in an ongoing investigation into the proper duties of society and medical professionals to life. Centered largely on duties to human subjects in both research and clinical care, bioethics has been enlarging its domain for decades, encompassing now questions of duties to animals, ecosystems, and nature in general. Because of its extensive reach, for its progressive growth we depend upon constant questioning, new ideas, and challenging cases. Given the rapid pace of technological and societal change, there is never any dearth of material to explore and every international conference and congresses like the one documented in this book offers an opportunity to learn, discuss, debate, and grow our discipline and collegial environment.

The World Congress documented herein was just such an instance, and we have attempted to capture as much of it as possible, including plenary sessions and other highlights over the course of four days in downtown Mexico City. Mexico's own recent commitment to engaging the public at large, and internationally, with bioethical issues served to foster many of the discussions and debates with which attendees

grappled. Moreover, the experts, scholars, and practitioners who attended brought to the table experience, cases, and points of view that we hope will be of interest and benefit to anyone engaged with bioethics, either professionally or casually.

We have compiled for posterity, and to enrich the international scholarship and discourse in bioethics, the plenary sessions and other noteworthy events from the 12th World Congress. Minor typographical and grammatical editing as well as some standardization of prose are the only editorial additions to the present work. In every instance, the words of the speakers as they delivered their addresses were preserved as much as possible to maintain the semantic content. The following pages should serve as a memory of the event, and as a launching point for the next World Congress, and future meetings, workshops, and conferences. We look forward to continuing this dialogue and engaging with this community of researchers and all others who, finding these talks inspiring, decide to pursue bioethics.

CONBIOÉTICA is very pleased to issue this report, which is but a subset of the engagement we were pleased to host, which nonetheless provides the essence of the discussions at the core of the World Congress.

I am confident this information will be helpful to all those interested in bioethics over the world, national governments, international organizations, academics, and the general public. ◗

Manuel H Ruiz de Chávez
President of the 12th World Congress of Bioethics

President of the Council of the National
Bioethics Commission of Mexico

ACKNOWLEDGMENTS

The organizing committee of the 12th World Congress of Bioethics wishes to thank the many organizations and individuals from Mexico and abroad who have assisted its work and helped make the Congress and this publication possible, specially Secretary of Health Mercedes Juan; Enrique Cabrero Mendoza, Director of the Council for Science and Technology (Conacyt), Julia Tagüeña, Deputy Director of Scientific Development, and Lorena Archundia, Director of Science Planning also at Conacyt; José Narro Robles, President of the National Autonomous University of Mexico (unam) and Jorge Linares, Director of the unam's Bioethics University Program, and our partners: the Secretary of Foreign Affairs, the Secretary of Health of Mexico City, the National Council for Culture and Arts, and the Mexican Health Foundation.

We also thank the International Association of Bioethics (iab), especially Inez de Beaufort and Angus Dawson, who supported the whole conference organizing process, providing sound advice on logistic and academic matters.

Special mention to Ambassador Sandra Fuentes-Beráin Villenave, whose support was essential in accomplishing such a great conference.

Likewise, we acknowledge the excellent job made by scientific committee members Angela Ballantyne, Carlos Viesca, Daniel Fu-Chang Tsai, Deborah Diniz, Farhat Moazam, Florencia Luna, Hans van Delden, Jaime Burrows, Jaqueline Chin, Jorge Linares, Kris Dierickx, Lisa Eckenwiler, Manuel H Ruiz de Chávez, Michael Selgelid, Raúl Jiménez, Ruth Chadwick, Ruth Macklin, Søren Holm and Thalia Arawi.

In addition, the organizing committee is very grateful to the Advisory Committee members: Guillermo Soberón Acevedo (President) —Mexican Health Foundation, Guillermo Miguel Ruiz-Palacios y Santos —National Commissioner of the National Institutes of Health and High

Specialty Hospitals, David Kershenobich Stalnikowitz —Director of the National Institute of Medical Sciences and Nutrition, Gabriel O'Shea Cuevas —National Commission of Social Health Protection of the Secretariat of Health, José Ramón Cossío Díaz —Supreme Court of Justice of the Nation, Juan Ramón de la Fuente —National Autonomous University of Mexico, Juliana González Valenzuela —Faculty of Philosophy and Literature of the National Autonomous University of Mexico, Enrique Ruelas Barajas —National Academy of Medicine of Mexico, and Enrique Graue, Director of the Faculty of Medicine, UNAM.

Special thanks also to CONBIOÉTICA's council members Emma Verástegui, Paulette Dieterlen, Lizbeth Sagols, Cecilia Rodríguez, Enrique Beascoechea, and Rubén Lisker, and the whole National Bioethics Commission of Mexico.

Without the assistance of all our national and international partners who have offered exemplary financial and organizational support, the 12th World Congress of Bioethics and this book could not have been possible. The organizing committee recognizes the support from Casa Cuervo, S.A., Café Punta del Cielo; Fondo Nacional para el Fomento de las Artesanias (FONART); Museo de Arte Popular (MAP); Rotoplas, S.A. de C.V., Grupo Bursátil Mexicano (GBM) and Turycon. ◗

The Organizing Committee
for the 12th World Congress of Bioethics.

PREFACE

This century promises to pose challenges beyond what we can today anticipate, and already confronts us with significant new dimensions of necessary inquiry in almost every realm. In the realm of bioethics, where technology, society, and individuals meet regarding one of our most personal and essential values, we should expect a flood of new and difficult ethical, legal, and societal questions, many of which will lead us into debates for which we are only partially prepared. The scope of the subject of bioethics appears to continue to expand, embracing areas in almost every science. This is happening in part due to the convergence of various technologies, and in part because we are recognizing the breadth of ethical duties once perceived to be limited to medical care and clinical trials. The traditionally identified bioethical duties of beneficence (non-maleficence), dignity (autonomy), and justice have been debated and reconsidered, fine-tuned and adopted beyond bioethics as a niche, and in fields of public conduct of science impacting humans less directly as subjects. Bioethicists now are an increasingly diverse category, encompassing philosophers, medical professionals, attorneys, and numerous others who come into contact with issues impacting health, the environment, science, and technologies.

Bioethics reaches beyond academia too, although its roots and intellectual home remain there. Providing a rich base for research, the field has generated degree programs at every level, research programs, and continued public and private sources of support. Bioethicists are immediately engaged with the broader public in almost every issue for which there is ongoing research. Its close nexus with public policy ensures that almost no research is ever purely academic. Events on bioethics, such as the World Congress around which the experts contributing herein were assembled, offer a diverse mix of exciting

insights into a rapidly developing and spreading array of interests. The range of topics discussed in this compilation of talks is vast and deep, and the expertise offered by those participating ranged across dozens of discrete but interconnecting disciplines.

Congresses such as those memorialized in part by this book are vital opportunities for the fruitful collision of theory and practice. Given its multidisciplinary nature, and its roots in both active theory and practice, bioethics evolves largely through a dialectical process. Theories clash with each other and with cases, which are often considered the core of bioethical investigation and pedagogy, and through this clash new manners of thinking, new consensus, and eventually policies emerge. Those policies directly affect science, global environment, and human health, as well as rights and dignity. The world around us is shaped by discussions such as these, and the researchers and practitioners whose dialogue help change the world meet at venues such as the 12th World Congress, reflected in the pages herein.

Consensus or agreements about topics addressed by such dialogue are necessarily contingent. As with any investigation, new evidence can lead to falsification, opinions can change based upon new information, and factual context can shift. This is why the bioethical process remains a dialectic, in flux, open to new evidence and points of view. The discussions expressed in these pages are ongoing, not final. Tomorrow, new cases, new technologies, new social phenomena may arise or shift in ways that we cannot now predict, and cause us to have to revisit our previous conceptions.

We are engaged in this ongoing dialogue, this attempt to address the ever-changing fields about which bioethics must necessarily concern itself, as a means ultimately to improve the human condition. Ultimately, we are in the great tradition of humanism, but reaching out into a biosphere that encompasses much more. Global climate change, animal ethics, ethical duties towards generations, and eventually even issues like exobiology will become subjects of our studies. Here we see researchers and active practitioners grappling with these and other issues, as well as questions about culture, meta-theoretical questions, and highly practical questions about policy in the here and now. The consequences of this study and the necessity for the continuation of

this dialogue seem never to have been more urgent than now. Faced with global urgency, with fears of pandemics, rapid and perhaps uncontrollable technological change, societal upheaval, and broadening notions of duties, we must look forward and face new issues with new perspectives, challenge our preconceptions and devise new coalitions of researchers, theoreticians, practitioners, and citizens.

The pages below are graced with the best of the best among those who contribute to this growing field, and bioethics has never been more vibrant. We expect that you will find material that provokes, that incites concern, that raises questions and disagreements, but above all, that helps to move this area of inquiry forward productively. Whether you are already involved in bioethics professionally or casually, we expect too that you will be encouraged by the various manners and approaches by which the field is addressed in these papers to confront these topics in your own ways, and to contribute too to its ongoing development, however you can. We hope you do, and look forward to your own contributions to this dialogue, this exciting and growing field called bioethics. The World Congress was, for many, a peak experience, but the peak of this field has not and will likely never be reached. Future congresses will build upon this one, and the reflections in the coming pages will serve as the foundation for the dialectic of which these ideas are a constant part. These memories are a tribute and provocation for ongoing research, and new ideas not yet considered. We are encouraged and humbled by the depth and breadth of the contributors and their commitment to the field, and to the betterment of humanity through their research and thoughtful engagement with pivotal issues. We hope you will agree as you peruse the chapters to come. ◗

David Koepsell
Srategic projects and research coordinator
National Bioethics Commission of Mexico

1. THE IAB WORLD CONGRESS OF BIOETHICS

The International Association of Bioethics (IAB) World Congress is perhaps the largest single meeting related to bioethics in the world. Its focus is on the promotion of original findings and new theoretical perspectives surrounding the ethical issues that emerge from the advances of science and technology. Discussions include debates about humans, animals and the environment as a whole.

The IAB aims to be truly international, linking all those working in bioethics and related fields, facilitating mutual contact, and encouraging the discussion of cross-cultural aspects in bioethics.

Since 1992, the International Association of Bioethics, according to its objective, has fostered the organization of the World Congress of Bioethics facilitating communication and promoting discussion over academic, scientific and cultural aspects related to this discipline.

Although this is the 12th World Congress of Bioethics the previous eleven congresses have been events of the foremost importance, and today, with this task, we confirm their continuity and validity. From 1992 to this date, there has been a journey and a significant learning in the field of bioethics.

The 12th World Congress of Bioethics

For the 12th World Congress of Bioethics, held from June 25 to 28, 2014 in Mexico City, the host was the National Bioethics Commission of Mexico (CONBIOÉTICA).

This meeting was an ideal place for the convergence of diverse international networks of researchers in specific areas of bioethics, such as the Ibero-American Network, the Bioethics Education Network and the Environmental Bioethics. Four satellite meetings were also

held: the International Network on Feminist Approaches to Bioethics, the Global Forum for Bioethics in Research, the Workshop for Early Career Bioethics Scholars and the Conference on Bioethics, Public Health and Peace for Indigenous Peoples, this last event took place at the Tlatelolco Cultural Center on Saturday, June 28.

For this conference, the objectives included:

- Interaction with the most important experts in the global field of bioethics. Exchanging experiences and establishing links for the future.
- Identifying innovative trends in the field of bioethics, including original knowledge and its development and application.
- Strengthening actions that promote the solid presence of bioethics in the Latin American Region, both in the academic fields and in research, teaching, and practical performance.
- Promoting the social transcendence of bioethics and its impact in the daily life of citizens, in the drafting of public policies, as well as in the international recognition of Mexico.
- Promoting bioethical knowledge as an expression of culture and as an instrument for personal and collective development, for the care of health, protection of life in all of its expressions, and the preservation of the environment.
- Discussing and reflecting on diverse bioethical considerations pertaining to human rights, equality, intercultural processes, and the prevention of discrimination.

In this 12th edition, the Congress' attendees witnessed thirty keynote lectures, fifty symposia featuring 170 international experts, 290 abstract presentations and 78 poster presentations by academics, researchers, health professionals, as well as graduate and undergraduate students.

The themes addressed in the congress were grouped into four main categories: Global Health, Science, Society and the Individual. ◗

2. OPENING SESSION

2.1 Mercedes Juan,
Secretary of Health, Mexico

Manuel H Ruiz de Chávez, president of the National Bioethics Commission of Mexico and of this 12th International Bioethics Congress; Guillermo Soberón Acevedo, former chairman of the National Bioethics Commission of Mexico and former Secretary of Health, thanks for joining us here today. Angus Dawson, former president of the International Association of Bioethics; a special welcome to Julio Frenk, former Secretary of Health of Mexico, who will be one of the keynote speakers.

I'm proud of the work we've carried out during the past few days of the 10th Global Summit of National Ethics/Bioethics Committees, where official representatives of national bioethics commissions from member countries of the World Health Organization had the opportunity to discuss and analyze national and global public policy regarding ethics and health.

It is an honor for Mexico to host the 12th World Congress of Bioethics, an event of considerable academic and scientific prestige, which brings together specialists from around the world and opens up a vital space for sharing information, analysis and viewpoints about the development of this branch of science. I'd like to congratulate Manuel H Ruiz de Chávez for the organization of this Congress around the central theme of "Bioethics in a globalized world: Global Health, Science, society and individual," where a dialogue will be established to join and direct efforts towards building a global culture of bioethics.

As we all know, one of the goals of bioethics is to preserve the rights and dignity of people, as well as the environment. This discipline enables us to address ethical dilemmas relating to health care from

birth through the end of life, as well as those that arise in research with human subjects.

This issue is of utmost importance to our country, since our president, Enrique Peña Nieto, has called for the creation of a society of laws in the framework of a more egalitarian, more inclusive and globally responsible Mexico. One result of this has been the strengthening of the National Bioethics Commission; another has been the creation of bioethics commissions in each state of Mexico.

The General Health Law was reformed in 2011 and now obliges all public and private institutions that offer health care services or conduct research with human subjects to create hospital bioethics committees focused on analyzing conflicts of values and bioethical principles that may arise during the medical attention process, but also research ethics committees, which are collegiate, institutional and interdisciplinary advisory bodies whose purpose is to evaluate and issue opinions on protocols for research involving human subjects.

Bioethics is involved in a number of public policy concerns and is, thus, an integral part of national planning processes. It can be considered a strategy for action that transects all the substantive activities proposed in the Sectorial Health Program for 2013-2018. On the issue of universal health care, for ten years now Mexico has had a social health protection system that includes a universal catalog of health services, including 285 treatments that cover 100% of the demand for care among people not covered by the formal social security system, in addition to a protection fund that covers catastrophic expenses, which includes more than sixty illnesses. In this area, it is very important to review the different factors for incorporating treatments and groups of illness, based not only on epidemiological, clinical, and cost-benefit criteria but very importantly, ethical and bioethical criteria that are important in making coverage decisions.

Our dear friend Julio Frenk was responsible at the time for making the complex decision regarding the first treatments that would be covered by the Catastrophic Expense Protection Fund. We all know that in health, there is never enough money to address all the needs of the people, so difficult decisions must be made about what sort of public health care services can and should be offered.

Ten years later, we are fortunate to have the support of prestigious scholars like Norman Daniels, who will be speaking at this conference and has been involved in going over the successes and missteps of the Catastrophic Expense Protection Fund, taking into account all the social security institutions in the future, bearing in mind the issue of universal coverage.

There are ample areas of opportunity to promote a bioethical culture in Mexico, and the ground is fertile for introducing projects and programs that will help further develop this discipline. I am confident that this 12th World Congress will be of the utmost academic and scientific importance for disseminating findings and new perspectives regarding the ethical issues involved in scientific and technological progress and its potential consequences. These challenges will also require that we follow up on the legislative side, to remain consistent with the bioethical aspects.

I'd like to extend my best wishes to all the expert speakers and guests at this event, and my hope that your contributions to the global knowledge and practice of bioethics may be fruitful. Good luck.

Today, June 25, 2014, I declare that the 12th World Congress of Bioethics is officially open; may it be for the common good of all humanity.

Congratulations, and thank you very much for your attention. ◗

2.2. Manuel H Ruiz de Chávez
President of the 12th World Congress of Bioethics

Mercedes Juan, Secretary of Health; Søren Holm, President of the International Association of Bioethics; Guillermo Soberón, former president of the National Bioethics Commission of Mexico; my dear friend Angus Dawson, president emeritus of the International Association of Bioethics; all of them members of the groups that have met and contributed to making this congress a reality.

Of course, I must not fail to recognize the members of the state bioethics committees, and very particularly the members of hospital committees on bioethics and research ethics from all over Mexico. My dear friends, members of the International Association of Bioethics, I would like to extend you the most cordial welcome to our meeting.

I'd like to express my sincere gratitude for the invaluable support of the Secretary of Health of Mexico, the National Science and Technology Council, the National Autonomous University of Mexico, the Board of Directors of the International Association of Bioethics, and, of course, the National Council for Culture and the Arts, which gave us a great deal of support on the cultural side, but particularly Mercedes Juan, Angus Dawson and Inez de Beaufort, for their sound counsel and recommendations on organizing this Congress.

I am also grateful for the efforts made through the *Guillermo Soberón* fellowship, granted by the National Bioethics Commission, and, of course, with the support of the National Science and Technology Council and the Secretariat of Health, which made it possible for so many distinguished participants to join us from Turkey, Argentina, Cameroon, China, Lebanon, Nigeria, Ecuador and Colombia.

I'd also like to recognize my colleagues from the National Bioethics Commission, the people who have joined us from the Program on Bioethics of Mexico's National Autonomous University. Thanks are due also to our distinguished guests, who with the authority and recognition they have in the field of bioethics, will speak and give us the honor of offering keynote speeches in the sessions that will enrich this meeting.

Today, all of us on the National Bioethics Commission of Mexico are very pleased to have brought together 1,248 conferees, making

this possibly the largest meeting on bioethics in the world. Today the efforts of almost two years crystallize here; in this gathering of experts on bioethics and other interested parties from more than seventy nations and all 32 states of Mexico. In the 22-year history of the National Bioethics Commission, which I have had the honor of presiding since 2009, this week is probably its most important moment as regards actions for dissemination, analysis and reflection on bioethical knowledge. I am confident that it will serve as a vitally important turning point for the development and consolidation of a bioethical culture in Mexico, in the Americas, and in the entire world.

It is my great privilege and honor to welcome you to this 12th World Congress of Bioethics in Mexico City.

Bioethics present and the future

This is an era of increasingly fast change and exciting new challenges in our various fields of interest, and under the general rubric of bioethics we are having many emerging opportunities to share our ideas, apply our experiences, and graze new ground. Bioethics as a field is one of the more fully developed of several related applied ethics disciplines, owing its now established development to early progress in clinical medical ethics, ethics, and —more recently— questions that have arisen as ethics in biological research, which have become a public concern in the last fifty years.

Here we have gathered representatives from many nations, from all corners of the world, scholars, clinicians, philosophers, counselors, ethics committee members, and others, whose combined and collective interests in bioethical issues confirm that continued progress in the field will occur and spread. It is part of the testament of the success of bioethics that it has combined these various fields and others, bringing together disparate groups with different interests, and implementing policies and institutions that now apply theory and principles in tangible ways to protect human life. It is also part of the success of the field that it has come to be a field of its own, distinct from its origins, a niche where people can spend whole careers both innovating and practicing, and to which a growing body of international

laws, principles, regulations, and practices underline its far-reaching scope and relevance.

What does the future hold in our field, and how we will solve the problems posed by emerging technologies and new possibilities? How has bioethics paved the way for other niches of applied ethics, and what can it teach us as we confront global issues like climate change, biosecurity and dual-use concerns, animal rights and GMO technologies, and more complicated issues in human subjects' research? How these various issues relate, and is bioethics as a discipline evolving to accommodate these and other issues, or will new niches be necessary?

If the past fifty or so years of applied ethics, and bioethics in particular, have shown us anything, it is that academic and practical niches often interrelate in ways we never anticipated, and that complicated challenges to our preexisting notions often provide opportunities to re-assess, and seek common ground where we previously thought there was none. How do the duties of caring for medical patients interrelate to concerns over the uses of human subjects in medical science, or to potential duties we owe beyond humanity?

For centuries, perhaps, we became used to the notion that there is something special about medicine, and afterwards medical science, and perhaps also about biology, and so concerns over the ways that we interact with the biological world are also special. We also, along the way, became more aware that the biological world is embedded within the social world, and that duties to human society drive us to regard our actions to patients, or to individual subjects, as also socially directed actions for which broader duties may also be warranted. In other words, the scope of our duties seems to grow, with each new alarm when something goes wrong, with each new story about preventable harms, or those we never expected.

Society demands that our errors be amended, that we learn from our mistakes, and that the future becomes better, less potentially harmful, and more potentially fruitful. Scientists and researchers in an ever-expanding domain of fields are arriving to similar conclusions, becoming aware of the broadening scope of their duties, and experiencing greater scrutiny. The expansion of research ethics to

engineering, physics, social sciences, and other niches has been impelled by ethical lapses similar to those we use and study as cases in medicine and bioethics. The potential for harm from ethical lapses outside medicine, outside the biological sciences, and fields in which we never before considered applied ethics are necessary or even important, is becoming ever more real. This is because, all this time, our preconceptions about who is a subject, and who might be being used in some manner in the application of science through technologies, may have been too narrow.

Since Nuremberg, we have learned that despite our very best intentions, and despite a history of errors, wickedness, and ignorance, we are still prone even in our best moments to make errors in judgment, miscalculate our duties and the effects of our actions, and to be myopic about the future. We have attempted to guard against these tendencies in a number of ways, including through the ever-clearer enunciation of principles, education, and finally the creation of an ever-more-stringent and universally adopted institutional form of protection. We still seek to know whether, how, and to what extent all of these efforts are effective, and how they might still be adjusted to fulfill the needs for which they were created. There is so much yet we do not know, and recognizing these gaps in our field propels us forward through a gathering like this.

Bioethics has room for so many interests, disciplines, experts, and questions. It is this rich and adaptive milieu that attracts so many to its study. We should also be mindful of its great accomplishments, even as we debate and study the various approaches to its embedding in society. Moreover, we should be aware of its adjoining fields, anticipate future concerns, and make room for more adaptation. As biology, for instance, converges with engineering in domains like synthetic biology and nanotechnology, will bioethical concerns spill over into engineering and its particular ethical issues or vice versa? Do technologies or practices that affect the environment more generally fairly fall within bioethical concerns given that, arguably, we are all human subjects in global experiments? Where medical research simultaneously poses security concerns, as with research into H5N1 and other deadly pathogens, how shall we weigh apparently conflicting

duties? We can see that the future of bioethics is very rich, complicated, and truly multidisciplinary.

Those who have expressed concerns that philosophical ethics has focused too narrowly on medical ethics in its application can take comfort in the very real need to remain mindful of the origins of its study, the continued relevance of the tools and methods of ethical reflection and basic theory, and the increasingly philosophical nature of all ethical reflection in the sciences. Here, in the next few days, we will examine just a very few of the great many emerging issues the world will face, and bioethics can contribute to. We are fortunate to have opportunities such as these, and to live in the time we do, where such a diverse group of experts, offering so much, in such a variety of ways can potentially help with real global issues. Our biological world is embedded in a rich social realm, and the duties we owe clearly envelope so many domains that a truly open-minded and pluralistic approach is necessary. It is why we are here, and why so many of you, fresh faces, and established experts, have gathered to hear from each other, to listen, to share, and provide guidance for the next fifty years and beyond.

Thank you for coming, we are excited to have you here, and I look forward to learning from each of you. ◗

2.3 Søren Holm

President of the International Association of Bioethics

Dear friends and colleagues, on behalf of the International Association of Bioethics, it is a great joy to be here. For our organization, it is very important to have a truly international dialogue about bioethics, which is not dominated by only some voices from the global North.

It is therefore, very important for us that we are able to host the conference in different places around the world. We are immensely grateful to the National Bioethics Commission of Mexico, to the Ministry of Health, to the National University, for beeing willing to take on the quite onerous task of holding this congress.

We are immensely grateful because it is also very appropriate that we have a congress in Mexico. The National Commission of Bioethics is a leader in bioethics, not only in Latin America, but also on the world stage and has been so for many years. Mexico itself is a leader in developing health-care systems that are suitable for middle- and low-income countries. By being here, I hope that we can all benefit from the immense knowledge and contributions of Mexican colleagues and perhaps to a lesser extent they can benefit from our contributions.

On behalf of the International Association of Bioethics, it corresponds to thank the organizers and thank all of you who have chosen to attend this congress and who, I am sure, over the next days, will make this the best International Association of Bioethics Congress ever. ◗

3. KEY NOTE SESSIONS

3.1. *Crossover* FAB-IAB session

Chairs: Angus Dawson and Manuel H Ruiz de Chávez
Ruth Macklin. Health, Safety, and Women's Human Rights
Søren Holm. Families, Obligations and Genetics

a. Ruth Macklin
Health, Safety, and Women's Human Rights

Respect for culture. We are told that we must have respect for culture, but how far should respect for culture take us when a culture fails to respect the human rights of women? I am going to describe what is known in the literature, largely feminist but also other literature, as the "rape culture."

There are some of the elements of the culture of rape: blaming the victim; it is common to hear "if a woman wears provocative clothing, she asked for it;" trivializing sexual assault, with expressions like "boys will be boys;" tolerance of sexual harassment, particularly in the work place; gratuitous gender violence in movies and on TV, defining manhood as dominant and sexually aggressive and in contrast defining womanhood as submissive and sexually passive; refusing to take rape accusations seriously, and publicly scrutinizing a victim's dress, her motives, and in particular in court cases, her past history, and finally jokes about rape.

To show some of those elements, here are some comments by prominent men, mostly taken from newspaper accounts. The first was the former president of Pakistan, who was quoted in September 2005, in a newspaper in the United States, the *Washington Post*, who said, "A lot of people say, if you want to go abroad and get a visa for Canada, or citizenship, and be a billionaire, get yourself raped." The second

comment is by a conservative columnist for the *Washington Post*, who recently was talking about what he called the "supposed epidemic" of sexual assault on college campuses in the United States. He said, "When universities make victimhood a coveted status that confers privileges, victims proliferate." This was another way of almost blaming the victim. Finally, the former chief minister of the state of Uttar Pradesh in India, who made this comment after a gang rape that occurred in India, "Boys are boys, they make mistakes."

Some statistics to show the world crisis of rape. From 1971 to 2012, the recorded cases of rape in India have gone from just under 2,500 to almost 25,000 annually over that forty-year period. Activists claim that only 10% of cases are reported to the police. South Africa is other State that has a very high incidence of rapes, one of the highest in the world. These are mostly estimates, statistics are hard to obtain because most rapes are not reported and this is actually true everywhere in the world, there are fewer reported rapes than actually occur. One study estimates as high as 500,000 rapes over a two-year period between 2011 and 2012.

An emblematic case is the sad tale of Olivia Zinnah, a beautiful little girl in Liberia. When she was nine years old, she was found to be severely malnourished and handicapped. The doctors determined that her condition was a result of a brutal rape that occurred at seven years old. Olivia named her twenty-year-old cousin as the rapist. They lived in a rural area of Liberia and because they sought outside help, their own tribe shunned them. As part of what she underwent at her ordeal, her father left the household and her grandfather, who was a tribal chief, and sided with the rapist. Many women in the community accepted the male culture that endorses this behavior. One woman was quoted as saying, "Raping a child is considered a good-luck move. They do it for a ritual purpose." The police arrested the rapist, but then they released him and there was nothing further about that case. In 2012, Olivia died of septic shock related to her injuries. Even though she had some good doctors in Monrovia, Liberia, they were never able to fix her after the brutal rape. This was all depicted in a documentary film called *Small, Small Thing*.

Rape in India. According to different accounts, some by human rights lawyers, the situation for rape in India is complex because the police are part of the problem. A human rights lawyer in New Delhi was quoted as saying, "If you are a woman in distress, the last thing you

want to do is go to the police," this was quoted in the *New York Times* in January 2013. Another quotation from the same person, "Many women say the presence of the police makes them seem less safe, not more... In case after case, the police have used their powers to deliver women into the hands of their abusers."

In an article written by an Indian woman on an editorial page, referring to what she called, "India's feudal rapists" the role of the cast system in India's rape crisis was part of what she was depicting. She said, "A twelve-year-old and a fourteen-year-old girl were raped and hung from a tree in the state of Uttar Pradesh earlier this month. The girls were of a lower caste than the group of brothers who raped them" and "When the father of the girls went to the police, they asked him what his caste was and when they found out that he was among the lower castes they refused to act." Caste-based sexual violence and other forms of violence are actually condoned and culturally accepted in the community where this episode occurred.

However, India does have laws, and the problem in some places is not the absence of laws, but the absence of enforcement of the laws. Back in 1989, a law was passed, the "Prevention of Atrocities Act," that was designed to address caste-based violence in India, but apparently it is hardly enforced and the conviction rate is described as "notoriously low."

In this context, not all is bad news. India has been responding to the problem of rape with a public movement against violence toward women, with hundreds of people marching in the streets, and this is part of the good news story. Also, a former Chief Justice in India, who was appointed to head a committee established to amend existing law in India in response to a brutal gang rape of a woman, who subsequently died from her injuries in December 2012, issued a report with a chapter entitled "Gender justice and India's obligations under international conventions," where he cites several human rights declarations and treaties, like the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), and the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW).

Mass sexual assaults in Egypt. A coalition of feminist groups documented more than 250 cases of sexual assault at public gatherings

between November 2012 and January 2014. Human rights advocates blame Egypt's patriarchal culture for the frequency of attacks on women in public spaces. Most recently, women were hospitalized after attacks during the presidential inaugural celebrations on June 2014. Human Rights Watch reported what they called an "epidemic of sexual violence" in Egypt. The Egyptian President later apologized with a victim publically assaulted by the crowd that was celebrating his election.

Rape in Latin America. While it is not the case in all countries of Latin America, according to some accounts in twelve Latin American countries, rapists can be exonerated if he offers to marry the victim and she accepts. The family of the women frequently pressure her to marry the rapist to restore the family's "honor." These cultures are known as "honor cultures," they exist even outside of Latin America.

Sexual assaults in us military. According to the Department of Defense of United States, sexual assaults in all branches of the United States Armed Forces rose 6% in 2012 to 3,374 cases. Of these, only 302 went to trial, leading to 238 convictions. Estimates from an anonymous survey indicate that in 2012 there were 26,000 sexual assaults in the United States Military. The vast majority are not reported, which is why the anonymous study shows much larger figure than the official statistics.

Sexual assaults on campuses, in universities in the United States. A government task force reported that one in five female students on college campuses were sexually assaulted. Only 12% of those are reported. Rapes have occurred at very prestigious universities such as Yale University and Dartmouth, two of the so-called Ivy Leagues schools.

There was a rape allegation at Florida State that was not investigated by the police. It was believed that the reason was that the university did not call the police. The person accused to be the rapist was a star football player of the university. Just like in almost any country, the sport stars are idolized. The prosecutor declined to file criminal charges. The Police Department has since begun working with a woman's advocacy group to revise its sexual complaint policy.

The us Congress passed Campus Sexual Violence Elimination Act in 2013, which requires that domestic violence, dating violence, sexual

assault, and stalking cases must be disclosed in annual campus crime statistics. In January 2014, President Barak Obama created a task force of senior administration officials to coordinate federal enforcement efforts.

Rape as a weapon of war and conflict. The United Nations has a declaration of commitment to end sexual violence in conflict. In this regard, a chief prosecutor of the International Criminal Court in Hague pledged to step up the court's investigation and prosecution of sexual and gender- based crimes. The Global Summit to End Sexual Violence in Conflict took place in London on June 2014, where representatives of 120 countries, including more than 900 experts from NGOs, survivors, faith leaders and international organizations, developed an international protocol on the documentation and investigation of sexual violence in conflict to set standards for collecting information. It urges countries to strengthen their domestic laws for prosecutions, both in and out of countries where sexual violence occurs.

A rights-based approached to causes of women's death and harm from sexual assaults should invoke the International Covenant on Civil and Political Rights and the Convention on the Elimination of all Forms of Discrimination against Women. There are provisions in these international documents, not only for governments, that is, the signatory states, but also for non-State actors. In addition, there is the Istanbul Convention, a treaty specifically on preventing and combating violence against women and domestic violence, and the Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women that was adopted back in 1994.

Conclusions. The continuation of culturally sanctioned sexual violence against women could be remedied only by gaining control of the social factors that are causally responsible. There are human rights provisions and even laws but the laws are no adequately enforced. The steps that are needed are attempts to demolish the factors that constitute the rape culture.

All governments that have ratified the International Covenant on Civil and Political Rights, (CEDAW), and other international human rights treaties, have an obligation to respect, protect and fulfill the

human rights of the many women in their countries who are sexually assaulted, and bring the perpetrators to justice. To strengthen the actions to eliminate the epidemic sexual of violence against woman, involvement of men and the whole society is essential.

b. Søren Holm

Families, Obligations and Genetics

Hilde Lindemann's recent book *Holding and Letting Go–The Social Practice of Personal Identities*, in page 148, asks us to consider two half-brothers Ned and Sam who have grown up without knowing about the existence of the other. Now, Ned needs a bone marrow transplant, so he becomes aware of Sam's existence. What are Sam's obligations?

We have two people genetically related, but perhaps not related in any other ways. What Lindemann claims is, first of all, that it is intelligible that Sam should see Ned as his brother and also intelligible that Ned could feel hurt if Sam declines to donate; second, that Sam is part of Ned's family tree and the connection between them is not simply biological; thirdly, that our current practices show that genetic family ties matter socially. I will accept the claim one and three, both independently and jointly because the intelligibility found in one is partly produced by three. I will deny a strong reading of two.

My interest in this topic is because of my own family history. I am a third-generation adopted child: I was adopted, my father was adopted, and my father's mother was adopted. I happen to know that I have at least three younger half-siblings, of whom the only thing I know is that they exist, or they hopefully exist, or that they existed. If I got a letter or an email from one of my half-siblings, would I have a greater obligation to answer it than if I got one from a stranger? Perhaps yes I would, but my argument would be that even though I ought to answer the email, the answer could legitimately be that I think that we are strangers and that I want it to continue to be that way.

Why is the question important? We have Ned- and Sam-like situations where health care needs are at play. Assisted reproduction and general societal developments in family structures are likely to

make the existence of unknown or almost unknown genetically related persons more common. It is likely to become easier to find unknown genetically related persons if you want to find them.

There are three different kinds of family relations identified in literature: Genetic family, social family, those that in a particular society are recognized as my family, and affiliate family, whom I think of as my family. Our pre-reflective views of familial obligations track none of these family relations perfectly because they diverge; it also means that, except for genetic family relations, being in a family tree is not transitive. I might be in your family tree and you might not be in mine.

Of course, there are many societies where only certain kinds of genetic relations generate social obligations. So, how do we identify our "moral family"? Those that we are linked to in a way that generates moral obligations that are different with your obligations behold towards pure strangers.

Lindemann points out that if Sam was considering whether he should help Ned, and is tending towards the view that he has an obligation to help, it is not an adequate rebuttal of obligation to say, "But you're only genetically related to him!" On the other hand, if Sam was tending towards the view that he has no obligations, it is not adequate rebuttal either to say, "But you are genetically related to him!" Now, the reason for this is that both of these rebuttals are actually begging the question. They are both implying that the issue of the importance of genetic relatedness is settled.

Why might bare genetic relatedness matter? We could think it is all about evolutionary psychology; we are hardwired to prefer kin, because kin-preference increases inclusive fitness. The problem with this argument is that inclusive fitness is not ethically important in itself. It is not ethically important how many of my genes are spread to the next generation. The other problem is that by the same argument we are probably also hardwired to display out-group aggressiveness and in-group preference (otherwise known as "racism") and many other problematic attitudes in this position. The fact that we are hardwired in a particular way by an evolutionary past doesn't really tell us much about how we should act.

Genetic relations may also make us especially suited to help. One of the reasons that Ned wanted to contact Sam is obviously that there is a larger chance that Sam is a suitable donor because they are related

in this way. If we take that genetic relatedness makes us especially suited to help as a reason that we have obligations, this just shows that people are more suited to help due to strong obligations whether or not they are more suited due to genetic relatedness or some other factors.

If instead of Ned and Sam we think of Ted and Pam. Ted needs a donor. So he searches available gene profiles on the web. He finds that Pam is a good possible donor, despite the fact that they are not related. He contacts Pam. Does she have any obligations to help? Is that obligation different from Sam's? What we take to be our moral family is not a matter of genetic relatedness, it is a matter in which genetic relatedness plays a part, but it is dependent on social facts and our specific family history.

Genetics also plays a large part in our discussions about assisted reproductive technologies. One of the reasons that this matter makes clear is that there are a lot of people who have strong preferences for genetic relatedness. They have a strong preference for the child that is being created or related to them in a genetic way. These preferences are perfectly intelligible. It is perfectly understandable why in our society you would feel that way, and it would continue to be perfectly understandable even if genetic relatedness does not really matter morally. Preferences might still matter.

This still leaves a question of whether there is anything more of ethical importance in having a genetically related child than is a preference for this outcome. What makes my son be my son? And what makes me willing to make significant sacrifices for him? It necessarily has very little to do with genetics and much more with social interactions, we share a history. Nine months before he was born is an important part of that history, the exact point at which he was conceived is a less important part, but he would be mine even if we did not share his conception at the gestation.

When we talk about genetic in relation to assisted reproduction, we are not talking about children who are ours, who are not genetically related to us and we don't know it, we are talking about cases when we know that they are not genetically related from the start. Why would we think that genetic relatedness matters in assisted reproduction? We might think again that it is a hardwired desire that it is simply a matter of evolution or fact; we are hardwired to want genetically related children. That might mean that the preference of

desire is difficult to get rid of, but, of course, the fact, that something is hardwired evolutionarily doesn't mean that it is rationally required.

We have to distinguish it from a preference for gestation, birth, and early connection. All of these preferences are also completely intelligible but they are unrelated to genetics. The important thing here is that when we are having a genetically related child through assisted reproduction, it is a joint product, project of the couple. Then, genetic relations to one parent seems to be good enough in many assisted reproductive contexts. We have ideas about what we are doing when we are having children, that it is somehow reproducing either ourselves or the family name and line. Of course, this doesn't tend to show that genetic relatedness is morally important. The most we can say for the desire to have children who are genetically related to us is that it is completely understandable and not irrational. Whether it is a morally good desire still needs to be shown. ◗

3.2 Session 1

Chair: Eduardo González Pier
Tom Beauchamp: *Why We Needed the System of Research Ethics We Have and How It Needs to Change*
Norman Daniels: *What are the Roles of the Courts and Health Systems in the Progressive Realization of a Right to Health?*
Julio Frenk Mora: *Ethical Foundations of Health Policy*

a. Introduction

The field of bioethics is attractive to those from numerous disciplines partly because it encompasses so much. We have a truly diverse set of issues, constantly evolving, and vigorously debated in the public and academic spheres. It is a constantly evolving body of research and a growing area of knowledge. Moreover, because of the changing nature

of our multicultural milieu, new viewpoints are constantly introduced into a fluctuating dialogue. The field, though mature among various applied ethical disciplines, remains new in many ways, and its founders remain among us, able to share their guidance, wisdom, and provoke and challenge our assumptions. As with many fields of both research and practice, categories and distinctions have developed that were not always planned, but that came about organically, *ad hoc*, or by regulatory fiat. Not all of these distinctions survive; others do so through habit or stubborn adherence to custom. Yet matters still change, states of affair evolve, and customs alter or die.

Most philosophers look for sources for modern bioethics in ethical theories, devised and refined by philosophers over the last couple millennia, and adopted into modern bioethics through a number of important and familiar historical events. The implementation of ethical principles through formal institutions associated with medicine, however, is quite recent and is often traced back no further than the Nuremberg code, referenced repeatedly by the contributors in this publication. In truth, and as noted by Professor Beauchamp, the code was just an acknowledgement of duties, but left sometimes unfulfilled the difficult task of implementing those duties, holding responsible those who failed, and formalizing their application for decades. Even now, there remain significant gaps and questions regarding the reach of the principles first enunciated by the Nuremburg court, and later adopted by the Belmont report, and the framework erected upon its adoption by regulation. As with many areas of evolving ethical concern, adoption of codes and even the creation of regulatory mechanisms did little to resolve *a*) the sources of breaches of ethics, and *b*) questions regarding the proper reach of the principles and formal arrangements created.

Most of applied bioethics, and its progeny, including research ethics, focuses on work done in the name of science, and leaves unchecked both philosophically and practically the vast range of human activities in both sciences and technology that are not part of "research" *per se*, but rather commerce, industry, innovation, or some combination of these. Yet is there any evidence that, except for the realm of biomedical research, humans are not somehow treated as subjects, used to some degree in the development of new products,

subjected to potential harms as serious or more serious than those faced in the narrow realm of biomedical research? In fact the vast history of science and technology is replete with harms caused either directly or indirectly, sometimes to entire populations as well as to individuals, because duties were not clear, actions were not measured, or failures of consent were present.

Medical research has never been conducted the same way as many of the other sciences, mixing rather freely the necessities of clinical practice, sick patients needing help, and trial and error. Medical doctors face exigencies that other researchers would appear not to. Medical patients are more directly in touch with researchers than most human subjects of research are, and the nature of medical care and research remain in flux. The boundary between medicine and other sciences and technologies is similarly questionable and age-old assumptions are being challenged. Likewise, the nature of medicine and health in society is in flux.

Whereas medicine was for a long time a private matter of negotiation between physician and patient, subject to the vicissitudes of the market, due to the rapid advance in technology and associated costs, the delivery of standard medical treatment has become, almost everywhere, much more expensive. As a result, the nature of transactions between patients and physicians has also changed, as have the relations between clinical care and medical research. These changes are interrelated and pose significant social concerns. How shall we fairly distribute both the costs and benefits of increasingly effective and expensive medical care? To what extent must society contribute, and under what theory of responsibility?

Both Norman Daniels and Julio Frenk address from differing perspectives issues relating to access and right to health or health care. The worldwide crisis in ensuring accessible health care has in part been wrought by the great advances made in the 20th century in the quality and effectiveness of medicine. The price has been increasing costs and hierarchies of access, such that the wealthy are often able to afford levels of care that are increasingly unavailable to the poor or even the middle classes. The United States is often cited as the last of the industrialized and developed economies to affect some form of universal coverage, although in truth the model adopted is far from

universal health care. Developing economies such as Mexico had beat the us to the punch by enacting some form of universal coverage legislation nearly a decade before the us, but affordable and effective health care remains out of reach for people throughout the world, and the breach between the level of care available to the "1%" and everyone else is not narrowing. The next century will pose significant challenges to the affordability and accessibility of increasingly expensive care, coupled with increased longevity and hopefully significant breakthroughs in treatments for chronic and widespread diseases. Will medical research and development keep pace with a stressed social fabric, or will entirely new models of health and medical research evolve necessarily in accord with our notions of justice? Time will tell, but it is not too early to begin discussing and planning as our contributors below urge us to do.

b. Tom Beauchamp
Why We Need the System of Research Ethics We Have and How It Needs to Change?

My presentation concerns whether we have good reasons for the division of the biomedical world that we make into research in practice while requiring ethical oversight systems only for research. First, I will discuss how and why required ethics review committees emerged in the 1970's with the burdensome network of rules and oversight systems for clinical research, while creating nothing truly comparable for clinical medicine. Second, I will look at why we need to change the current system —that is to say, the current oversights systems that we have— to incorporate clinical medicine, not merely research. Third, I will look ahead to the way that health-care systems that we have known ideally should be reconstructed to integrate health care with research, with information feeding back to the health care systems while also creating better systems of ethics. Much of what I have to say is dependent on a project team with whom I've been working for several years, mostly at John Hopkins. I owe them a great deal for the ideas on this talk.

I start with a key historical question, at least key for me. When did we first come to appreciate that there was a profoundly important need for a system of human research protections? I believe that no truly meaningful and widely accepted human research protection systems appeared prior to the late 1960's to early 1970's. More precisely, the prime start-up years were 1971 to 1974.

Although the Nuremberg Code has often been proclaimed the earliest influential code, it is a poor choice in my view for the beginning of organized protections. Americans drew up the Nuremberg Code specifically for the trials of German physicians. For two decades after it was issued, the code was either ignored or explicitly rejected in every country known to me, including the United States, East Germany and West Germany. For our part in the United States, we never took Nuremberg seriously, even though an American military court had declared it in effect the moral law of research ethics.

We now know that during the years 1946 to 1966, there was an astonishing degree of moral ignorance and insensitivity in many institutions of biomedical research, despite what had happened, and was well known to have happened in Germany. It is also well known that the United States Government and some of this country's premier universities and institutions were, at the same time of the Nuremberg trials, engaged in paradigm cases of research scandals. These now infamous scandals should not cause us to lose sight of how bad the situation had become in various parts of the routine, not the extraordinary, but the routine affairs of biomedical research. This was the thesis defended in the famous 1966 article by Henry Beecher, who showed how embedded moral misconduct was in clinical research. Beecher implicitly showed that we had learned nothing from Nuremberg, and that we had no embedded or codified system of research ethics. We soon thereafter concluded that research must be systematically regulated.

The most critical period is 1971 to 1974, because it was the period of laxity and scandals began to turn around in the face of protections, and then escalate dramatically. The sweeping policy changes in the 1970s at the federal level in the United States required most human research to be overseen by a system that included ethics peer review, prior to conducting research, an adequate consent process, special

attention to vulnerable subjects, and alike. This system of impartial third-party oversight was not imposed on clinical practice, only on research. There is one common belief about his history that I want to challenge. It is often been reported that the United States Senate hearings on experimentation in 1973, and the subsequent deliberation of the National Commission for the Protection of Human Subjects between 1974 and 1978, presumed that only research needs regulation, not clinical practice. This is an undue simplification, in truth, a falsification of the history.

The Senate hearings on human experimentation chaired by Senator Edward Kennedy had a significant focus on what might be called the territory between research and practice, but called at the time "practice," a territory at the time also commonly referred to as "innovative practice." Senator Kennedy's concern, as well as those who testified before him, was that vast areas of medical practice escaped ethical scrutiny because the innovators presented themselves as engaged merely in the routine practice of medicine. Kennedy was concerned, and so was the National Commission, that the most dangerous area of medicine might be clinical medicine of this sort, not organized research medicine. For political reasons, not overtly political reasons but unavoidable ones, this thesis could not be pursued either by Senator Kennedy in the Senate or by the National Commission, so it dropped from the scene of all academic discussion, but from the political scene.

This political situation was the background for a public law that created the National Commission with a special mandate to establish the boundaries between research and practice. The public law seemed to presume that there is a close and clear distinction between research and practice —one simply has to figure out how to determine what the boundaries are between the two. However, legislators did not figure out how to draw that line, nor in my view has anyone else. The commission settled for a document, the Belmont Report, which laid down the conditions that must be satisfied for an activity to be research, knowing that its criteria did not even begin to address the problem of unapproved innovative practice. In truth, that problem was put on hold and shelved, not resolved, and, in my view, it has never been resolved to this day. So much then for the historical background and

thesis. Now I want to use this history to turn more to ethics and public policy.

The domino paradigm in research ethics of oversight systems has rested on a segregation model that splits up clinical medicine and clinical research into two very separate domains. The National Commission, between 1979 and 1978, in its deliberations, as far as bioethics is concerned, created this model. It did not pre-exist. This Commission created two criteria in the model that have ever since been widely used to distinguish research from practice. These two defining conceptual features supposedly distinguishing research from practice are, first, research designed to develop generalizable knowledge where generalizable knowledge is the key conditions; practice, by contrast, is designed solely to help the patient at hand. Second, research requires systematic investigation and collection of data; practice, however, has no systematic investigation and data collection.

I challenge the clarity and acceptability of these conditions as a way of distinguishing research from practice, and I challenge the need for the distinction in our institutions in a way in which it is pervasive today, and I believe the problem is going to become more acute in upcoming years. Consider the first criterion of generalizable knowledge. This notion has never been carefully defined or analyzed in government regulations or in scholarship, and nothing clearly identifies it as outside the bounds of clinical practice. In my view, generalizable knowledge is no longer serviceable; it's the primary criterion to differentiate clinical research and clinical practice, and to tell us what should be regulated or have an oversight system. I expect our system of the delivery of health care to increasingly become an environment in which clinical centers are directly engaged in research and their clinical services are constantly being improved by the data received. Here, data assimilation and use for patients will become integral in attaining the best practice of medicine, not merely something done by remote research.

Accordingly, I believe a better model than the current segregation model is an integrated learning healthcare center designed to simultaneously deliver the care that patients need, while capturing the experience of clinical practice in systematic ways that produce what we think of as generalizable information, in order to directly improve

care in the present and future patients. In an integrated healthcare center, the production of generalizable knowledge will simply be part of the practice of medicine. The segregation model distinguishing research from practice will, I believe, increasingly become obsolete. If this hypothesis is justified, it is time, I believe, to consider whether we should restructure our current system using an integration model. This is particularly true, I believe for bioethics.

The US Institute of Medicine report seems correct in stating that we are now, and I quote, "Drawing research closer to clinical practice by building knowledge development and application in each stage of the healthcare delivery process." In this conception, measurements taken in the course of clinical care are recorded with the intent that these measurements be used both to modify patient care and to feed information to on-going studies in the constant loop. This system is designed to simultaneously treat patients at hand and facilitate new knowledge. As such systems are developed, and we are certainly only in the very primitive stages of having such systems, research in treatment will become increasingly integrated, not segregated. Growing numbers of activities in healthcare institutions already cannot comfortably be classified as either research or therapy, or the one excluding the other. For example, participating in a clinical trial may be regarded by a woman with melanoma as her best treatment option, even if the specific treatment she receives is determined by random assignment. As the second example, quality improvement in patient safety research, designed to evaluate whether various kinds of reminders of drug interactions might reduce medication errors, does not alter the patients' experience of clinical care, stands to improve clinical outcomes for future patients and may improve outcomes for patients who are receiving the care while this intervention is being tested.

Since the 1970's, the view has been deeply engrained that research with patients is riskier and less likely to produce net clinical benefit than is clinical practice. This view has been an important part of the rationale for regulating and reviewing research, but not practice. However, is research in fact riskier than practice? There is growing recognition that many therapies, tests and interventions used regularly in clinical practice are of unproven value and many may be harmful. The Institute

of Medicine estimates that more than half of treatments in current use in medical practice lack adequate evidence of effectiveness, and many surgical and diagnostic procedures disseminate into practice with a little or no prior scientific study. Mounting evidence indicates that patients in ordinary clinical care are often at risk of receiving sub-optimal outcomes and of being harmed, however inadvertently, as a consequence of an adequate evidence use of unproven practices and biases in clinical judgment that might be corrected.

Substantial evidence now points to the frequency and severity of the clinical harms patients experience as a consequence of medical errors in lack of supervision in health care. The exact number of patients harmed from health care is unknown: there are no reliable overall statistics, but we know that approximately 100,000 people die annually in the United States from healthcare acquired infections. Approximately a 10,000 die from healthcare related venothrombo-embolism and many thousands die from care that results from teamwork failures, medication error, falls that occur at healthcare institutions, diagnostic errors and medical device errors. We do not know how much of this harm can be avoided, but where focused, targeted improvement efforts have been tried most of the harms have been found to be preventable. I'm not denying, of course, that research studies expose patients to risks of harm: of course they do. The point is that standard care does too. There is simply no good evidence to support the long-standing empirical assumption creating the split-segregated system that I mentioned earlier, to support the long-standing view that research studies as a class are more likely than clinical practice to run counter to the medical best interests of patients.

I turn finally to a profoundly important issue about ethical oversight and committee review. Unlike the research context, third party oversight is generally not required to ensure ethical use of interventions of unproven clinical benefit and unknown risk in clinical practice, or to systematically avoid diagnostic and other forms of errors. There is little, if any, prospective moral scrutiny of practice comparable to the scrutiny of research, and practice context can put patients on unjustifiable and avoidable harm. For example, patients may have surgery at the hands of surgeons or teams who rarely perform such

an operation, despite empirical evidence that low-volume hospitals have worse outcomes than high-volume hospitals. In important respects, these patients are experimental subjects, not merely patients, often without their knowledge or consent. Medical error and other clinical risks, therefore, need to be supervised and monitored, much if they are in research. Protection from harm is the underlying moral problem and should be our premier concern. It should not matter whether the harm occurs from what we categorize as research or categorize as practice. It has been a mistake from the very start that we require review only of research.

This kind of under-protection of patients in practice is one side of the problem. An overprotection of patient subjects is another side that I really can't get into, but requiring that all activities that are designed to produce generalizable knowledge and that collect data systematically must undergo prior review by an ethics review committee, even when patients clinical care is in a respect changed, is a misplaced moral criterion of what needs review. Requiring only what is classified as research to undergo the burdens and costs of extensive oversight, creates disincentives to rigorous learning, and is costly unregulated. Thereby, increases the likelihood that interventions will continue to be introduced into clinical practice and healthcare systems in the absence of scientific evidence to evaluate their effects. That's obviously a disaster of the system if that's the system that we are perpetuating.

I conclude. The idea of organizing healthcare institutions as systems in which research and practice are seamlessly integrated did not exist when regulatory bodies governing research involving human subject were initially developed. Our now well-established system has served us really commendably well in certain respects, especially in overcoming these scandals I mentioned earlier, but we need today to identify more efficiently which interventions work, how errors can be reduced and when interventions or tests should be administered or avoided for groups of patients. It is time to reassess our empirical assumptions about ethics review, what needs ethics review, ethics review models and the like, with the goal of coming to a more balanced understanding of what matters morally, which is the same in both research and practice, namely, protection from harm.

c. Norman Daniels

What are the Roles of the Courts and Health Systems in the Progressive Realization of a Right to Health?

It's a considerable honor to be here; especially on a stage with people I've admired my whole life. In any case, I want to talk about an issue which is pressing in Mexico and is also pressing in many parts of the world where there is a right to healthcare, or right to health, in the Constitution, because, I want to talk a bit about the role of the courts and the healthcare system in addressing the notion of a right to health.

To clarify the role of the courts and the healthcare system in progressive realization over right to health, or more narrowly, health care, we must first understand what such a right is and what its entitlements are. In my view, the justification for a moral right to health and healthcare lies in a theory of justice. Such a moral right can be embodied in a constitution where it becomes our legal right with similar entitlements. The recognition through treaties and international covenants of a human right to health, or health care, also makes the entitlements of such a right progressively realizable in light of reasonable resource constraints. My picture is that resources —there are always resource constraints, some more reasonable than others, but we can't avoid that problem because health care in health is not the only good that a system or society has to address. When we try to invoke resources and use resources to promote health, we have to think about these other goods as well. On my view, the central goal of health policy are to promote population health and distribute that health fairly. This involves the progressive realization of a right to health.

I do want to say one word in beginning on the notion of distinguishing a right to health from a right to health care, because, no doubt, the philosophers in the room will jump on my back for talking about a right to health. But what I've been persuaded by is that health has many determinants and I believe the fair distribution of those determinants is a social obligation-giving rise to the right to health. Some determinants of health keep us healthy by reducing the risks of ill health, such as traditional public health measure and a fair distribution of the social determinants of health. Medicine, in contrast, aims to keep us healthy

once we are sick, although it too can provide some prevention for various kinds of illness, so access to health care is also a right on my view because there is a right to health. Of course, saying we have a right to health does not mean that if we get sick and die then our right to health has been violated. It only means that the fair distribution of the factors that society can control is something that we have a right to.

A right to health or health care, I have elsewhere argued, is a special case of a right to fair equality of opportunity, and I won't repeat those arguments here. This conception of a right to health or health care starts with the assumption that we have a right to fair equality of opportunity, and the protection of our health makes it significant if limited contribution to the preserving of those opportunities, so we can think of a right to heath care as an implication of a right to fair equality of opportunity.

How a society invests resources in meeting its obligations to protect population health and distribute that health fairly, the goals that sometimes, conflict matters greatly. Yet, there will be reasonable disagreement about how to allocate resources to that task. Each resource allocation has an opportunity cost that must be considered; specifically, every treatment that is provided can be replaced in this allocation by treatments for other conditions, each of which has other claimants for care. If we provide one treatment, we cannot provide the others; at least I'm assuming that. These are the opportunities we miss because we can assume we can provide one treatment. We have to make sure that the treatments we provide do not displace more important treatments that we could provide. Even if some intervention would cure an individual of a condition, his or her right to health or health care does not imply that that treatment is owed to that individual if the opportunity cost providing it is too great. Perhaps, other claimants to health care should be treated instead. A plausible claim is that an individual has an entitlement to a treatment if it is something that a healthcare system fairly decides to include in the array of services it offers to all in need, given its constraints on resources; some individual claims to treatment would not be among those in such an array. Since reasonable resource limits mean that not everything can be done for everyone in need. The progressive realization of a right to health means that we cannot deduce that a specific

treatment for a specific condition is in entitlement of that right unless the treatment is part of an array of services that the system concludes all must have access to.

Accordingly, a constitutional right that is progressively realized carries with it only those entitlements as well. So too, I argued, does a human right to health or health care that is progressively realized? Of course, the idea of progressive realization can become a disguise for a State unwilling to realize a right to health and health care, and it is often been served in that role. The idea behind progressive realization is sound even if the concept is often abused. With limited resources we cannot do everything that we could do with more resources, and so we must progressively realize a right.

This view of the relationship between a constitutional right or human right to health or health care, and the entitlements such a right involves, has implications for the role of the courts and of the health system; specifically, the court should not conclude that a right to health or health care means that any and every effective treatment, regardless of cost, is something that people with that right are entitled to. To decide that a specific treatment is an entitlement or a right to health care under reasonable constraints, a court would have to determine that the opportunity cost of providing that treatment is similar to the opportunity cost of other treatments that the health system does include. Properly done, that is a task and a responsibility of the health system since it, not the courts, is in a good position to judge the opportunity cost of treatments it includes, which doesn't mean that health systems always do a good job at that, since they often do not.

The task of the health system is to implement a fair deliberative process through which decisions about the inclusion of new treatments are made. The court should show appropriate deference to the obligation to this task to the health system, but it has the responsibility to make sure that there is progressive realization of a right to health or health care.

Herein lie both a threat and a promise that we hear about as a judicialization of the health system; I hope I don't have to say that word too many times. Judicialization poses the threat of encroaching on the proper tasks of the health system, which must use limited resources

to both promote population health and yet to distribute that health fairly, and this means treating all as equal possessors of a right to health or health care. Specifically, the fears that the courts will undertake a task they cannot perform well, namely the judgment about opportunity cost of treatments, which I'm assuming they cannot perform well. Where over these risks are increasing inequalities, not reducing them, since better-off individual usually have more access through the courts than worse-off individuals.

At the same time, there is a promise benefit. Since the courts may counter the power of vested interest in political lobbies to enhance or even increase health inequalities. I think there is a middle ground between the threat and the promise. It involves both the health system and the courts acting in a way that improves the progressive realization of a right to health or health care. The health system must better integrate different components of the health system and arrive at a more uniform set of decisions about the fair allocation of resources so that the different groups in the population all enjoy the contingent entitlements that the right to health care or health provides. This requires establishing, I think, a fair deliberative process for making those resource allocation decisions; neither the integration nor the implementation of that kind of fair deliberative process is easy to do, but neither is it impossible to do.

On the other hand, the courts must focus on judgments that have the prospect of reducing health inequalities while progressively realizing the right to health; now, does this mean taking steps to decrease existing inequalities in access to the courts, but it means showing due deference to the delegate or authority of the health system to make opportunity cost judgments in a fair and deliberative fashion. Showing due reference to a fair deliberative process requires that there is a process to which deference is owed. If equity across parts of the health system requires integration, including a fair process for resource-allocation decisions across these different components of the health system, then there has to be a real attempt at integration to evaluate and show deference to. Due deference to that process should also mean that rationales the process generates should be consistently applied. The courts can make sure that the right to health and health care is respected. Due deference to that process should

also mean that the rationales in the fair deliberative process should be consistently applied. The courts can make sure that the right to health and health care is respected equally for all people through oversight of the fair deliberative process implemented by the system.

In previous work, Jim Sabin and I developed a theoretical justification for various conditions that we think a fair deliberative process should meet. This very abstract account of what a fair deliberative process involves is something that in previous work under Doctor Frenk's supervision in part, when he was Secretary of Health in Mexico up until 2006, and with Eduardo González Pier's assistance. In 2006 we constructed a manual to adapt the approach to decision-making that we described. There Jim Sabin and I described in a very abstract fashion to the catastrophic insurance plan in Mexico, and the intention behind that was to use this as a test of a particular adaptation of a deliberative process in making the kind of decisions about expanding the resource allocation to new diseases in the catastrophic insurance plan that there was no good model for anywhere in the world.

We constructed this manual and it was adapted, divided the task into different groups for different participants; there was a clinical group and an economics advisory group and this is a flow chart depicting that, so the clinical and economics groups would work together, on particular disease conditions to present a recommendation to an ethics group which would make some recommendations, or they would present information to the ethics groups; the ethics group would make recommendations and these would be vetted by their social acceptability. It turns out that in the subsequent administration after Julio Frenk's, this process was not actually fully implemented, and that one of the main obstacles was that there was a lot of resistance to the social acceptability component. What exactly would it mean? How could one manage those groups? How do you prevent social acceptability judgments from turning into lobbying efforts by vested interests? That's an issue I think has to be worked on further and will be.

This manual was structured to test the ideal of could this very abstract idea of a deliberative process be adapted within the framework of Mexican laws that regulated the catastrophic insurance plan. Since that time, many decisions have been made about what diseases and conditions to add to the catastrophic insurance plan and these were

not made with the benefit of this process. My suggestion is that it is not too late to introduce an adaptation or revision or reconsideration of this process into the Mexican system, and if it did, it could become a model for integrating many key pieces of the healthcare systems and the benefit plans they offer in Mexico. I'm making a policy recommendation based on some background bioethical thinking about the considerations that would determine whether judgments are made in a fair and legitimate fashion. This is a proposal that is now under consideration and review by the Mexican system, so it is something that I hope could illuminate what the task of the Mexican health system is but also set some limits on what the role of the courts would be, because if this manual is implemented, I think that there is something for the courts to show due deference to, and to show some clear respect for, namely, an honest effort to make fair decisions about the resources uses to which these can be put in protecting people against the financial burden of these diseases.

I wanted to make a final remark about bioethics, because the picture I have, and it was somewhat foreshadowed by Tom Beauchamp's remarks that bioethics was born and raised and, as many people have noted, it was rooted in the dyadic relationship between doctors and patients, or researchers and subjects; it was also focused on the question, should we do everything we are able to do using new technologies? What I'm proposing, then, is that bioethics focuses well on whether health systems and courts are functioning in a way that promotes population health while distributing it fairly, so this I take to be an exercise in the bioethics and health policy that focuses on population health. Perhaps, that's because I now work under Julio Frenk in a school of public health that I've come to think about this as the central feature, the direction that bioethics should move in.

My claim is that this effort to pursue the two goals of health policy, distributing health fairly while at the same time improving population health, requires a concern about prioritization of how we use our resources and that's what I've been addressing. Bioethicists, in my view, must think about how we can best use our resources to accomplish these two goals of health policy and they have to do this for populations and they have to train more people to help them achieve those goals.

d. Julio Frenk Mora
Ethical Foundations of Health Policy

First of all, I would like to thank the International Association of Bioethics, especially Manuel H Ruiz de Chávez for the invitation to participate and for the organization of this Congress and also for his exemplary role at heading the Mexican National Bioethics Commission, which is a commission that has really generated enormous value in my country and that has been led by very major figures. I would only like to single out Doctor Guillermo Soberón, who also presided over this commission. I would like also to take this opportunity to honor the memory of Doctor Manuel Velasco Suárez, who also served in that capacity. It is an additional great honor for me to share the stage with Tom Beauchamp and Normal Daniels, two of the truly towering figures in the field of bioethics.

I'm not a bioethicist, but I have been in health policy positions, with deep appreciation of the central role that bioethics in this expanded conception that we have heard from the previous two speakers can play and that's why I have entitled my lecture, "Ethical Foundations of Health Policy," and you will see that my remarks will follow very nicely, especially from what you just heard from Norman Daniels.

What I want to discuss with all of you today is the use of an explicit ethical framework to guide in case of actual health system reform. As you have heard several times this morning, about ten years ago, Mexico embarked on an on-going structural reform intended to achieve universal health coverage and that reform is still ongoing. The main message of my remarks is that a clear ethical framework combined with technical excellence and political skill can deliver positive results for society.

The Mexican Reform was designed, implemented and evaluated, making explicit use of what my colleague at Harvard School of Public Health, Professor Michael Reich, has identified as the three pillars of public policy: the technical, the political and the ethical pillars. The three are closely interrelated since they must act in harmony to support the complex edifice of reform. Let me very briefly discuss the use of the first two pillars to then really concentrate my presentation on the ethical component. I have to say that over these ten years,

because this reform has been re-evaluated repeatedly, there's a literature of more than one hundred papers in peer-review publications. I'm just going to give a very brief overview, but anyone who is interested has access to a very voluminous literature on the reform I will discuss.

First, the technical pillar. The technical pillar of the reform was built on the intensive use of scientifically derived evidence. Much of this was derived from the local adoption of knowledge-related global public goods that were adapted to the specific circumstances of the Mexican context. Coupled with national data, these instruments revealed a critical deficiency; namely, that the health system in Mexico, like in so many other developing countries, simply had not kept up with the pressures derived from a complex, protracted and polarized epidemiologic transition, a transition whereby malnutrition, common infections and reproductive health problems co-exist with non-communicable diseases and injury.

With half of its population uninsured in the year 2000, Mexico was facing an unacceptable paradox. Today we know that health is a key factor in the fight against poverty, and yet, a large number of families were becoming impoverished because of healthcare expenditures. The reform was designed to correct this paradox by introducing a new public insurance scheme called *Seguro Popular*, or People's Health Insurance. This innovative initiative is now protecting over 58 million Mexicans who had until now been excluded from conventional social insurance, employment-based social insurance. If we add to this figure those enrolled in social security institutions and those with private health insurance, we can reasonably state that Mexico is on track to reach universal health coverage with financial protection.

Furthermore, evidence can empower policy makers with convincing means to challenge the *status quo* and promote change. In this way, evidence also helps to build the second pillar of reform: the political pillar. In the Mexican case, this pillar demanded the development of a consensus among all stakeholders through active conciliation of interests between private and public actors, federal and local authorities, patient advocacy groups, trade unions, legislators and political parties.

The consensus-building process culminating in 2003, when the Mexican Congress approved a major legislative reform to establish a system of universal social protection in health to be operationalized

through the *Seguro Popular* scheme. Needless to say, the construction of the political pillar does not end with the enactment of new laws, but must continue into the implementation phase, which is where we are now. To this effect, the new insurance scheme was deployed gradually over eight years, in other to allow for the necessary time to produce initial positive results that generated additional political acceptance. This is yet another example of how the technical and political pillars reinforce each other. Achieving consensus in the midst of a young democracy that was still groping its way into a new set of political rules was very much aided by ethical deliberation on the moral implications of the existing arrangements, which, as I mentioned before, excluded half of the population from effective social protection.

Let me turn now to the heart of my conversation: the ethical pillar of the reform. The starting premise is very clear: every health system reflects a series of ethical assumptions. Consciously or unconsciously, explicitly or implicitly, these assumptions are expressed in the distribution of healthcare benefits and in the organization of institutions. Alongside the formulation of technical proposals and political strategies, every attempt to reform the health system should begin by asking which values it should promote. In this spirit, the Mexican Reform was formulated and promoted on the basis of a guiding concept and a set of explicit values that are related to the idea that health care is not a commodity or a privilege but a social right.

The guiding concept underlying the Mexican Reform of 2003 was the concept of the democratization of health. According to O'Donnell and Schmitter, the term democratization implies the application of the norms and procedures of citizenship to those institutions that have been governed by other principles, such as coercive control, social tradition, and judgment of specialists or bureaucratic processes. The term "citizen" is associated with a range of rights and duties as defined within a constitution. In his seminal work, *Class, Citizenship and Social Development*, Marshall recognizes three types of rights enclosed in the idea of citizenship: civil, political and social rights, which in the English society were consolidated in the 18th, 19th and 20th centuries, respectively.

According to Marshall, citizenship culminates in the effective exercise of social rights. As a result of its democratization process, Mexico had made considerable progress in the exercise of political and

civil rights, but it was clear that the next great challenge was to ameliorate inequalities by assuring the universal exercise of social rights, including the right to health care.

This right was formally recognized by the constitution in Mexico two decades ago, precisely when Doctor Guillermo Soberón was Minister of Health, and under his tutorship, the Congress amended the constitution to recognize a right to health protection, which includes the right to health care. While there was an explicit recognition of this right, in practice, not everyone was able to exercise that right in the same fashion. Half of the population, by virtue of their occupational status, enjoyed the protection of social insurance because, just like in the United States, access to insurance was a benefit of employment. The other half, however, the self-employed, the unemployed, and everyone who is out of the labor force, that half of the population, which back then, in 2000, amounted to 50 million people, were excluded from access to any form of health insurance.

The formal recognition as a social right was already there when the reform started, but its actual implementation was only benefiting certain portions of the population. What was lacking was the definition of the explicit entitlements that ensued from such acclaim, and the financial and organizational vehicles to translate them into effective health services for all.

The definition of such entitlements in the recent Mexican Reform was based on the adoption of five explicit values, which we call social inclusion, equality of opportunity, financial justice, individual autonomy and social responsibility. Let me very briefly mention or explain those.

Social inclusion is based on the premise that all human lives have the same value and that health systems must represent instances where everybody, regardless of socio, economic or labor market status, receive similar treatment for similar needs.

Second, equal opportunity; this is based on the notion that inequality can be viewed in terms of differences, either in actual achievement or in the freedom to achieve, which is the real opportunity that we have to accomplish what we value. Health services should help each generation to enter life with the same opportunities. In this sense, ensuring a basic common floor of health care for everyone has the same sense of justice as access to primary education.

The third value, financial justice, means that individuals contribute to the health system according to their financial capacity and receive services according to their health needs. Out-of-pocket payments are unfair because they lead exactly to the opposite relationship: people contribute according to need; the sickliest pay the most, and receive services according to financial capacity. That's why this reform aimed to eliminate out-of-pocket payments because a fair health system is financed in such a way that services are free at the point of delivery and a large enough risk pool is aggregated to facilitate three types of solidarity: risk solidarity between the healthy and the sick, generational solidarity between the young and the old, and distributive solidarity between the wealthy and the poor.

The fourth value, individual autonomy, means that every person enjoys the freedom to decide what is more convenient for him or her, a prerogative that the family assumes in the case of minors and of people who are limited in their capabilities to decide.

Finally, social responsibility, the fifth value, places limits on the freedom proposed by the previous value. This is particularly important in the case of goods such as health services that exhibit what economists call "externalities," that is to say, consequences to others of an individual's decisions. Thus, neglect to care for one's own health has effects upon other persons. That's why, for example, in the Obama reform, the individual mandate is such an important part of the construction.

These five explicit values create the ethical foundation for the establishment of a system that provides through the *Seguro Popular* financial protection in health to all those Mexicans who had been excluded from the benefits of social insurance. The new scheme is mostly financed with public resources, and a small family contribution that depends on the level of income and is waved for the poorest 40% of the population.

The most interesting aspect of the new financial formula is that its point of departure was the definition and costing of the specific entitlements that would give operational meaning to the right to health care enshrined in the Mexican constitution. Specifically, the guaranteed entitlements comply two sets of interventions. First, a package of 285 what we call essential interventions for health conditions and these are conditions of high incidence and relatively low

cost which account for more than 95% of the amount of services, that is one set of entitlements. Then, second, there's a package of over 60 high-cost interventions that cover diseases with low, relatively low incidence but particularly with very high potentially catastrophic costs, and these now include treatment for HIV AIDS, cancer in children and cervical and breast cancer, among many others.

What I would like to discuss, to conclude, are the ethical implications of the use of a package of essential interventions, traditionally, an instrument of technocratic approaches to health care in a reform process that emphasizes equity and social justice. The packages of essential health services have been devised mostly as a priority-setting tool in a context of limited resources. Cost effectiveness analysis has been used to identify those interventions that can provide the largest amount of benefits for the available public resources, and these interventions are usually targeted to the poor. In the Mexican Reform, these packages did respond to the concerns for priority setting. However, their adoption wasn't reached through the incorporation of additional selection criteria. Their use as a planning and quality assurance tool and their extension to a universalistic conception of coverage, based on the explicit definition of entitlements.

First of all, we selected interventions making use of a broader set of criteria. We did use cost effectiveness analysis, but we also added this criterion in the law of social acceptability, which needs to be operationalized, but specifically the idea of social acceptability was to make sure that those interventions that were defined as priority conform to norms of behavior of the health professions and to broader social preferences. A second innovation was the package of intervention, which provided a blueprint to then estimate the resources required in order to strengthen the health system and make coverage really effective. Then, finally, the package was also used as a quality assurance tool designed to guarantee all the necessary services are offered in accordance with standardized protocol. For the first time, the new law requires that every facility be accredited in order to participate in the insurance scheme, and accreditation is based precisely on having the required resources to provide the stipulated interventions.

Finally, what I would like to stress the most is that the package has been used as an instrument for empowering people by making them

aware of their entitlements. In addition to the ethical dimensions, there are all these other uses of defining explicit entitlements. The interpretation of health or the transformation of health care into a real social right requires above all the definition of the set of health interventions that all citizens, regardless of their labor or socio-economic status, should receive and can legally demand. The new Mexican law clearly states that *Seguro Popular* beneficiaries would have access to all interventions included in both packages and to the respective drugs and other technologies. In summary, the Mexican model may be seen as an option to reconcile two extremes: the selective technocratic approach to the distribution of health care, which provides practical alternatives but pertains to be morally neutral, and the right-based approach, which has a strong value foundation but lacks operational support.

Let me make one last comment on the global implications. I'll explain this national case, but I think there are many global implications, particularly, those of using a rights-based approach to guarantee universal access to health care. What I would like to stress is the fact that social rights are human rights, or rights that everybody holds as a member of the human race. Therefore, the struggle to extend social rights, including the right to health care, transcends local legislations and the idea of national citizenship. This means that the demand for health care can come from anybody and not only from citizens of a particular country. This issue is particularly relevant given the level of migration that the world is witnessing. The implications of a right-based approach are clear: it is unethical to limit access to health services on the basis of the migratory or legal status of any person.

The human nature of the right to health care also implies that support from this claim can come from anywhere in the world. This opens an enormous field of action for international advocacy and global solidarity. In our turbulent world, health remains as one of the truly universal aspirations. It therefore offers a concrete opportunity to reconcile national self-interest with international mutual interest. More today than ever, health is a bridge to peace, a source of shared security, a way to give globalization a human face.

Let me finish by quoting the words of Michael Ignatieff. In the prestigious Massey Lectures delivered in Toronto in the year 2000, he

stated the following: "rights are something more than right legalistic phrases because they represent our attempt to give legal meaning to the values we care most about: dignity, equality and respect. Rights have worked their way deep into psyches. Rights are not just instruments of the law. They are expressions of our moral identity as a people. When we see justice done we feel a deep emotion rise within us. That emotion is the longing to live in a fair world. Rights may be precise, legalistic and dry, but they are the chief means by which human beings express this longing and it is important to understand that this longing is a global phenomenon." I would add that alongside the longing for justice, rights also generate a sense of belonging, since they point to our common identity as members of the human race.

It has been a privilege to me to share with all of you our longing for, and our belonging, to the global cause of justice through health. ◗

3.3 Session 2

Chair: Hans van Delden
Christine Grady: *The us Presidential Commission for the Study of Bioethical Issues and Compensation for Research Related Injury*
Juan Ramón de la Fuente: *Medicine and Human Values*
Jonathan D. Moreno: *Mind Wars: Brain Science and the Military in the 21st Century*
Amar Jesani: *New Clinical Trials (cts) Regulations in India: Bioethics Learns Through Engagement and Conflict*

a. Introduction

The genesis of much of the modern dialogue about applied ethics springs from concerns raised by revelations about treatment of human subjects in science, particularly in medical sciences. One of the ongoing

concerns of human subject use is the problem of justice, or the balancing of harms and who should bear them. Problems of justice typically emerge from imbalances in power, information, means, or some combination of these or other factors. Historical iniquities, ongoing social imbalances, and the standard hierarchies that exist among doctors, researchers, patients, and populations remain concerns when reflecting upon the justice of scientific studies, and ameliorating potential injustices, correcting for them in study designs, as well as accounting for new challenges in a multicultural and global system of health research pose significant problems for ethicists and researchers alike.

Historically, vulnerable populations have been used as subjects and subjected to real harms as a result with greater frequency that they ought. Doctor Grady examines not only the historical antecedents to current ongoing concerns about justice in experimentation, but also the very real problem of compensation for harms. As the recent HeLa cell line controversy makes clear, it is not always easy to identify who has suffered what harms in the use of human subjects (or their tissues) historically, but also it remains challenging to identify means of effective recompense, not only for ongoing studies, but also for past harms. How do we measure the cost of a life, ethically speaking? Legal systems grapple all the time with damage assessment in court awards for damages, but building into consent and authorization for use in clinical trials the potential costs of harms to subjects.

Institutional responses have been many and varied, and of still-unknown qualitative impact. Studies and commissions, regulations and legislation have attempted to bring some predictability and justice to the allocation of risks, harms, and compensation for the uses of individuals and populations in research. Absent international standards, market forces entice researchers to use vulnerable populations or individuals where the regulations are lowest, and where the costs of error are lowest. This will of course offend justice even further. One way to consider issues regarding the allocation of costs and benefits, and the just distribution of compensation for harms, is to ask questions about who benefits, to what degree, and at whose expense. Much more remains to be done to clarify the complicated nature of multinational, globalized studies and their potential distributed costs,

harms, and benefits, but there is a growing awareness of the need for a concerted approach to ensure greater justice.

Doctor De la Fuente notes that problems of justice are also reflected in disequilibrium in the nature and distribution of medical technologies themselves. In the same vein as a theme that has been explored above, medical services costs differently and deliver unequal measure of good based upon the degrees of advancement of various medical technologies. A net result is that medical care is unequal and access to the best care is not always possible, exacerbated by the costs associated with producing the best medical technologies. Add to this the fact that the costs in harms of producing superior technologies is often borne on the backs of vulnerable populations whose use is more costs effective to technologists and researchers, and the problems of medical justice in both research and development become more pronounced. Allocation of resources to health and medical concerns also poses a number of questions regarding justice, and the growth of new technologies has repercussions beyond our familiar concerns about justice, as we are reminded by Doctor Moreno.

A major international effort to delve into problems of neuroscience via a new avenue of research impacts our health costs, and poses new ethical dilemmas. In Europe and the US, two very costly efforts are underway to try to develop working artificial models of brains at various levels of complexity. The primary subject of interest is understanding how human brains work, developing better models of mental illness, and secondarily solving some of the so-far insurmountable problems of artificial intelligence research. These projects continue a research obsession that has, for fifty years, also resulted in some of the most well-known cases in biomedical and research ethics, raising questions about to what extent we can ethically research human behaviors where introducing chemicals, altering environments, and other interventions have sometimes caused significant harms. The human brain is the current super-subject of such research, but the autonomy and dignity of human minds is ultimately at stake in laboratories delving into its workings. To what extent will ethical concerns limit the use of non-human subjects of such research, including the models we create, and to what if any extent might such research reveal something important about the nature of ethical judgments themselves? The next twenty-

five years of brain research will pose these and numerous other ethical questions we have only just begun to explore.

Finally Doctor Jesani reminds of us the past few decades of use of subjects in India, a particularly ready market for medical experimentation of devices and drugs. Clinical trials involve significant risks and also significant potential rewards. A successful drug or device can mean millions, and subjects in developing countries pose a rich gold mine of testing. The nature of the relations between research and industry, and the potential for profit and risks of loss make both regulation and training in bioethical principles all the more important. Increasingly global and multinational research and industry demand more complicated institutional responses, both in the level of ECs and IRBs, and in the areas of recompense and legal response. Moreover, traditional western notions of autonomy become increasingly complex in the global milieu. We cannot assume that all subjects have equal access to knowledge and thus the same manner of abilities to give informed consent, and we must attempt to try to take into account the multicultural effects of global research programs, and their effects upon individuals in differing manners impacting justice. These authors pose helpful responses to the questions raised, and challenge us to discuss issues related to science, technology, and social justice.

b. Christine Grady

The US Presidential Commission for the Study of Bioethical Issues and Compensation for Research Related Injury

I am representing the US Presidential Commission for the Study of Bioethical Issues. I'm going to talk about an issue that has been important to the Commission, but is not the subject of a particular report. It is that the issue is compensation for research-related injury.

In the United States, the Presidential Commission was appointed by President Barak Obama at the end of 2009. We first met in 2010. We've served as an advisory body to the President. We are not the first commission in the United States. For the last twenty years, the commissions in the United States have served at the behest of the

President and so have lasted for the duration of the presidential administration and then, when there's a new president, there is a new commission. We've been in being since President Obama has been president.

Like many commissions around the world ours is multi-disciplinary, it's small. We have eleven active members at the moment with a variety of disciplines, mostly physicians, lawyers, scientists, philosophers, bioethicists. We've done seven projects thus far. Most of these projects, all of them (actually, except for one), have been done at the request of either the President of the United States or the Secretary of Health and Human Services. We haven't chosen our topics, we've been asked to do certain topics.

Today we are working currently on one related to the President Obama's recently announced BRAIN Initiative. But today what I wanted to do was talk about a little bit about particular recommendations that the US Presidential Commission has made regarding the issue of compensation for research-related injury, because this is a very important topic for the world, and one that's got a lot of attention in recent years. I'm going to spend a little time talking about the Presidential Commission's ethical justifications, a little bit about the current US regulatory framework and practice and a little bit about previous commissions' recommendations and then we go from here. That's the plan.

The commission recommendations about research across borders and moral science are reports on, sort of human subjects protections that I'm going to talk about a little bit more, and we have something to say about compensation for research injury in that projects. Then, the recommendation about safeguarding children was a very particular project looking at under what conditions it might be ethically acceptable to enroll children in research when we are studying interventions that might prevent disaster in bioterrorists attacks. So medical countermeasure research is a very specific issue.

The human subjects research project began with an *exposé* that occurred a couple of years ago by an historian at an university in the United States, Susan Reverby, who uncovered files that showed that there were a series of experiments in the 1940's done in Guatemala conducted by US researchers in collaboration with Guatemalan collaborators and funded by the United States. There were a number

of really serious ethical problems with the way this research was done. This uncovering of this experiment led the President to ask the Commission do two things: one, to do an historical investigation of what actually did happen in Guatemala in the 1940's. We did that, and there's a very detailed history of those experiments that you can get on-line if you're interested in that. Then, he asked us to make a survey of the contemporary situation to ask the question of whether or not the protections that we have in place today are sufficient to protect human subjects in US funded research, whether it's done in the United States or abroad and in particular, whether something similar to what happened in Guatemala could happen again.

As part of that project, one of the things we did is convene an international research panel. This is a panel that was convened for the purpose of discussing the sort of landscape of protections today, and also to make some recommendations to the Commission. We met three times, had very good productive discussions and summarized those discussions in the document "Research across Borders."

The document made five recommendations to the Commission. The first one was researchers must demonstrate respect for human subjects in their communities and gave a couple of ways that that could be implemented: through community engagement, through on-going international dialogue and collaboration, and through clarification of equivalent protections, a very particular issue related to our regulatory structure; that ethics training should be available for investigators, IRB members and others; we should have greater efforts to enhance transparency, monitor on-going research and hold researchers in institutions accountable; that the US should implement a system to compensate research subjects for research-related injuries; and that there should be continued efforts to harmonize and guide the interpretation of the existing rules rather than adding new rules for human subjects research.

I'm going to focus on the fourth one, the recommendation of this panel that the US should implement a system to compensate research subjects for research-related injuries. The panel discussed the fact that many countries provide protection for human subjects by requiring sponsors or investigators, or others, to provide or to ensure treatment for research related-injuries. In fact, it's often been said that the US lags

behind in this area, that we do not have a system that requires compensation for research-related injury. It is true that some US institutions carry liability insurance, there are other mechanisms whereby people get treated for the research-related injuries, but it's not a requirement for receipt of federal research funds in the United States. The panel felt that the US should consider creating a system, a system for compensating individuals in the event of research injury and actually suggested that maybe we should look carefully at a model that exists in the United States called the Vaccine Injury Compensation Trust Fund, which is a public model which allows people who have received vaccines to be compensated for adverse effects of those vaccines. Those are not research vaccines, those are already approved vaccines and most of those vaccines are given to children.

It is true that the current US landscape there is no US federal regulatory requirement to provide treatment or compensation for research-related injury. However, there is a requirement in the regulations that researchers tell people whether or not there is compensation and what that compensation might look like, so there is this sort of funny mixed message there in terms of what's going on. It's also true that although we don't have a federal requirement there's a landscape that's a bit of a patchwork. This study was done subsequent to the Commission's report and what these investigators did, they've addressed Nick and his colleagues, they surveyed publically available policies from the top 200 research institutions in the United States, top meaning those who receive the most research dollars from the Federal Government, and then described what the policy said about compensation for research injury.

More than half had no policy at all, no compensation offered. The other half had a mixture of what they described as "discretionary conditional and unconditional compensation." Discretionary, basically by their definition was policies that said "we might provide compensation for research injury," the conditional was "we'll provide compensation for research injury under certain conditions, like if the participant has no insurance, or that their insurance doesn't cover it, or the sponsor will offer it or something like that," and unconditional which can see as less than 4% of the institutions looked at unconditional, no conditions on compensations.

There are other parts of this patchwork, and I just want to allude to some of them. The NIH clinical center is where I actually work, does provide short-term care for research participants who are injured, but is explicit about the fact that it won't provide long-term care or financial compensation. There are other agencies in the US government, there is NASA, National Aeronautical Space Administration; they provide compensation for injuries based on a sort of work, kind of model. Medicare actually says it will cover the reasonable cost related to injuries but only as secondary payer, and what that means is if there isn't a first insurance company that would pay, then they won't pay. The University of Washington has one example, and one that is often cited in the United States: one university that chose many years ago to self-insure and they provide treatment in-house for research-related injuries and reimbursement for out-of-pocket costs. Then, there are private companies that sell liability insurance to institutions or research facilities that want to buy it.

However, it's been pointed out, and Lizzy Pike is an author who has done a fair amount of research on this topic, that the primary remedy in the United States for compensation for research-related injuries, is Tort Law. As she points out here, "It's perhaps out of inertia, awareness of the complexity of implementing a compensation system or a mistaken belief that injured research participants have adequate recourse in the court room that the United States has chosen to rely on Tort Law." She also points out that there are some groups for which Tort Law is very ineffective.

We see also in contrast to other countries around the world, but the report from the Commission very carefully tried to look at policies from many countries around the world and tried to document them so that we can see what the various options are.

The commissions, not recognizing that research is done for the common good, yet risks are borne by subjects and many of those risks are unforeseeable and unavoidable, really does believe that those who sponsor or engage in research have an ethical obligation to protect those who volunteer, and they describe this as encompassing two duties: primary protection from undue risk, and secondary protection which might be a means of limiting or reversing harm, through appropriate medical care of injuries. These are justified by principles

that many of you also have used in justifying this kind of program in other countries, justice including compensatory justice that compensates participants who volunteer to accept risk for the benefit of others, and reparative justice for those who are harmed from wrongful acts in research, as well as a recognition of a special duty of beneficence that researchers have towards participants based on the relationship with them to protect them from harm.

The recommendation says, "People who are research subjects should not have to pay all the cost of injury." But the recommendation goes on to say, "therefore, the Department of Health and Human Services should study what the best mechanism is for the United States." I want to say a little bit more about that. There have been actually four decades of commissions and task forces in the United States that have recommended some kind of system for compensation for research-related injury and we still do not have one. There have also been groups like the Institute of Medicine that has made that recommendation and certainly there are international guidelines that suggest that everyone should have a system, including the most recent addition to the Declaration of Helsinki.

But the problem is that all of these documents have significant variation in terms of substance of recommendations, in terms of whether a system should be implemented or should be further study but also the details of what the system might look like. What is the correct model in our context? Should it be a no-fault insurance system? Should it be federal grant compensations? Should it be a worker's compensation model? Or should it be based on the Vaccine Compensation Programme Model? Who should fund it? Should it be the Federal Government, the sponsors, the research institutions? What form of compensation should be offered? And which participants should be compensated? All questions that many people have struggled with.

Meg Larkin, who's a fellow member in our department who is doing some work on this topic, has suggested that the different ethical bases, that have been put forth for a compensation requirement, are pulling in different directions, and therefore, do not always align with the means of compensation proposed, and that very few scholars have addressed what types of harms should count as research-related harms that warrant compensation. A paper that was written about a

year ago sort of also talks about this issue. It describes the various different justifications that have been provided for creating a system of compensation for research injury and have actually put us into a situation of what it terms "moral gridlock," that they're pointing in different directions as to the details: who should be the responsible for paying, who should receive the benefits, what kind of benefits, and that we need to clarify which ethical justifications we want to follow.

There have also been lots of discussions, and lots of controversy over some of the details of a compensation program. How do we determine the injuries that are caused by research? Should all injuries in the research project be compensated for? Should all types of research injuries be compensated including pecuniary or spiritual? What degree of injury has to pertain in order to get compensated? What kind of remedy should be offered? Should it be treatment? Should it be compensation in terms of financial reparations? This all should be guided by ethical justifications.

The other recommendation that the Commission made was that, because this has been an on-going debate for many decades, that the Federal Government should study a system and come to some decision, but also should make a public statement if they decide not to do anything, to come out publically and say what are the reasons that they decided not to create a system for research injury. Let me say just one thing about the other report. This is the particular circumstance in which the children in a very sort of potentially risky or very precarious kind of research in which the benefit to society is somewhat more conditional and so we, the Commission, thought regardless of where the study might be done; in other words, in advance of some kind of an attack or subsequent to some kind of attack, a system for compensating any injury to the children in those research trials was absolutely mandatory.

In conclusion, I wanted to say that the Commission has agreed with, and articulated a clear ethical justification for treatment and compensation for research-related injury, but recognized also that there is a need for further analysis for regarding the specific implications on the ethical bases for such an obligation, and that those ethical bases might dictate the models of compensation that might be appropriate in our context, which injuries are compensable, which events are

compensable and who are the responsible parties, and that there are also many decisions that need to be made in any system about various elements, cause, type, degree, remedy and we're beginning to learn a lot about this from other colleagues in this room and other countries that have gone through some of these discussions themselves.

c. Juan Ramón de la Fuente
Medicine and Human Values

En los últimos años quienes hemos trabajado en los ámbitos de la salud, la educación y el desarrollo social, hemos podido constatar la importancia creciente de la compleja relación que hay entre la medicina académica, la salud de la población, la medicina asistencial y los valores humanos; todos ellos se nutren recíprocamente y unos dan mayor pertinencia a los otros.

Es oportuno examinar el asunto, toda vez que es en la perspectiva de los valores humanos, de la responsabilidad social de la medicina y del rigor intelectual con que se ejerza, desde donde pueden analizarse mejor y proyectarse con más autoridad los retos y las alternativas que permiten a nuestra profesión incidir con mayor autoridad y fuerza en el bienestar colectivo.

Empiezo por resaltar la importancia que en el contexto intelectual tiene precisamente la medicina académica, ésa que se sustenta sobre todo en la enseñanza y en la investigación, en el análisis documentado de los procesos que determinan la salud y la enfermedad.

Estos elementos son, además, los que permiten ofrecer la mejor medicina asistencial posible, sin prejuicios étnicos, religiosos o ideológicos, pero habría que agregar, por supuesto, que todo aquello adquiere verdadera relevancia sólo si se desarrolla en estricto apego a la ética del trabajo médico y el respeto cabal a los derechos de los pacientes y de sus familiares.

La medicina académica es, pues, sin duda, la que mejores posibilidades tiene de incorporar en la práctica los nuevos descubrimientos científicos; es también la única que ofrece expectativas reales de una formación sólida a los estudiantes tanto de licenciatura como de posgrado, y la

que, por el juicio crítico y el esfuerzo intelectual que demanda, puede ayudarnos a esclarecer con cierta sabiduría muchos de los grandes dilemas que hoy enfrenta nuestra profesión inmersa en la vorágine del desarrollo de nuevas tecnologías, el afán desmedido de lucro, la comercialización excesiva y, por si fuera poco, los fundamentalismos, que ahora pretenden erigirse en poseedores de la verdad absoluta y normar la conducta social de todos, sin excepción: médicos, pacientes, con base en su muy particular punto de vista.

Por añadidura, habría que agregar su potencial politización que ocurre tan frecuentemente en nuestros países. La salud no tiene, no puede tener partido político.

Hoy existe un desequilibrio entre los avances científicos y tecnológicos de la medicina, las necesidades humanas de los enfermos y los rezagos sociales de un país como el nuestro.

Aquí es donde la medicina académica debe mostrar, a través de los elementos que la nutren, su relevancia social si quiere contribuir a superar esos desequilibrios. Negarlos no tendría ningún sentido.

Necesitamos mostrarle a la sociedad que la inversión en los centros de atención médica de excelencia y de investigación, cada vez más sofisticados y costosos, es una inversión con alto rendimiento social; es decir, es una inversión para el bienestar; es en el ámbito de la medicina académica donde deben surgir además los lineamientos generales de las políticas públicas en salud: La regulación para el uso racional de las tecnologías y los medicamentos, los nuevos códigos de ética, los protocolos para la atención especializada, los tan rezagados cuidados paliativos, pues en México la gente se sigue muriendo con dolor, sin atención paliativa mayormente, para poder mostrar entonces y a plenitud las posibilidades de la medicina, esas posibilidades que hasta hace poco eran insospechables en muchos rubros, y de las que hoy disponemos por lo menos potencialmente para mejorar la calidad de la vida y también la calidad de la muerte.

Uno de los cambios más importantes que hemos experimentado en los últimos años es la influencia creciente que otras instituciones, tales como la industria y diversos grupos sociales, ejercen hoy en día sobra la salud, tanto en el ámbito público, cuanto privado nacional e internacional.

Es parte de la globalización. Las agencias multinacionales, las organizaciones sociales de todo tipo, las fundaciones, la banca de

desarrollo, las compañías farmacéuticas, las empresas biotecnológicas, los organismos gremiales, las aseguradoras médicas, etcétera, constituyen, todas ellas y muchas más, el complejo proceso, la multiplicidad de valores en los que hoy se desarrolla el trabajo del médico, el cual, además, como hemos podido constatar recientemente en nuestro país, se puede penalizar aún frente a la duda razonable.

Muchos de nuestros grandes maestros le dieron cuerpo, estructura, doctrina, sentido prestigio y misión a la medicina mexicana, con una perseverancia encomiable, con apoyos limitados, pero con gran autoridad moral, ganada a pulso a lo largo de muchas generaciones.

No debemos olvidar ese esfuerzo. Por el contrario, tenemos el compromiso con las nuevas generaciones de transmitir, y hasta donde sea posible enriquecer tan singular herencia.

Ése fue precisamente el sentido de la creación de la Comisión Nacional de Arbitraje Médico a finales del siglo pasado. Desafortunadamente, le han restado autoridad, y consecuentemente utilidad, dejando en manos de la justicia criminal el quehacer de los médicos, cuyos errores potenciales no hay que negar, pero no necesariamente los convierten en criminales.

Por eso, las posibilidades de servirle mejor a la sociedad, de las cuales hoy dispone la medicina, se sustentan en los avances de la ciencia, en la generación de nuevos conocimientos que mejoren la práctica médica, así como en la valoración objetiva de aquellos conocimientos novedosos surgidos en otras latitudes, para saber si es preciso adoptarlos o no en nuestras instituciones, si es conveniente incorporarlos o no a nuestro trabajo profesional.

Entender cabalmente qué es una moda —porque también las hay en medicina, por supuesto—, y qué es un cambio sustancial. Muchas veces ése es el dilema, y no siempre es fácil discernir al respecto. En ocasiones, sólo el tiempo es capaz de poner las cosas en su lugar. El riesgo es que lo haga demasiado tarde.

Lo que sí es claro es que a través de la investigación se pueden resolver muchos de los principales problemas de salud que hoy nos agobian, esa investigación que se hace, sobre todo, en los hospitales asociados a las universidades públicas, no por otras razones, sino porque son éstas las que hacen investigación en nuestro país, aunque haya algunas excepciones, por supuesto, que confirman la regla.

En un estudio que publicamos hace algunos años en la *Gaceta de la Academia Nacional de Medicina*, junto con Donato Alarcón Segovia y Jaime Martuscelli, mostramos que cuando se incrementan las plazas de investigadores, cuando se mejoran los salarios de los médicos y se dedican más recursos a proyectos de investigación sobre temas relevantes, como las enfermedades crónicas, las adicciones, la reemergencia de las enfermedades infecciosas, los accidentes, etcétera, no sólo aumenta la productividad científica, sino que aumenta la productividad en los centros de salud y en los hospitales; y los resultados de muchas de esas investigaciones locales se constituyen en los elementos esenciales para renovar las políticas públicas de salud con mejores resultados objetiva y rigurosamente evaluados.

Ésta es otra de las posibilidades del enfoque académico de los procesos de salud y enfermedad: evaluar con independencia, con objetividad, con rigor las políticas de salud pública.

Los centros académicos no deben subordinarse al poder. La libertad de cátedra y de investigación, al igual que la libertad de expresión, radica con frecuencia en saber decirle "no" al poder.

Por supuesto, se deben someter al escrutinio de los expertos todos los programas para conocer con objetividad sus aciertos y sus deficiencias, pero los expertos deben ser independientes.

Otro aspecto de enorme relevancia social, propio de la medicina académica y de los valores humanos, tiene que ver con la formación de recursos humanos en salud, incluida una amplia gama de nuevas disciplinas, que van desde las tecnologías más refinadas hasta la organización más eficiente de los servicios, así como el enorme reto que representa la modificación de pautas conductuales para la instrumentación eficaz de estrategias preventivas.

Me refiero a las enfermedades ligadas a los estilos de vida.

No basta, pues, con pensar que estamos haciendo las cosas bien, hay que probarlo, alguien tiene que evaluar, y se debe empezar por aceptar el veredicto de esas evaluaciones.

Al médico, al igual que a la enfermera y a los técnicos cada vez más especializados necesarios para ofrecer una atención integral de calidad, hay que formarlos simultáneamente en las ciencias experimentales que requieren de inversiones cuantiosas y en las disciplinas sociales y humanísticas, sin olvidar, por supuesto, la ética y

el delicado arte de la clínica, cuya enseñanza sigue siendo fundamentalmente tutorial.

Sin recursos humanos calificados no hay manera de que mejore la calidad de nuestro sistema de salud. Médicos, enfermeras y técnicos formados en el rigor de la academia constituyen los recursos más atractivos para la industria y para las instituciones médicas y centros de investigación en prácticamente todo el mundo; por eso han sido las áreas más afectadas por la fuga de cerebros, o movilidad del talento global, como le llaman ahora.

Despiertan tal interés estos recursos que muchos países, empezando por nuestros vecinos del Norte, modifican sin menor titubeo sus rigurosísimas leyes migratorias con tal de contratar a las enfermeras que requieren en ciertas regiones subatendidas, así como a los investigadores jóvenes que tienen posibilidades de contribuir al desarrollo de la ciencia y a todo aquel que esté técnicamente preparado para cumplir con una función específica dentro de lo que se ha dado en llamar "la industria de la salud."

Sigo pensando que en una sociedad más justa la salud debe entenderse como un bien público, al igual que la seguridad y la educación o el medio ambiente, y, por ende, corresponde al Estado la delicada, pero ineludible tarea de preservarla.

Por eso, estoy en contra de la imposición de un impuesto agregado a los ya costosísimos medicamentos; no le demos vueltas, el IVA a las medicinas es cargarles un impuesto adicional a los enfermos por el hecho mismo de estar enfermos.

Si se tiene en verdad un compromiso, no nada más con la salud, sino con quienes la han perdido y tratan afanosa y penosamente de recuperarla, no deben prevalecer los principios monetarios sobre las necesidades más preciadas, que son las más importantes de la vida, las que pueden hacer la diferencia entre recuperar la salud o dejar que ésta se deteriore, lo cual ocurre con mayor frecuencia entre los pobres.

La justicia social se alcanza con hechos, no con retórica. Lejos estamos aún de alcanzar la cobertura universal que tanto se ha pregonado.

Permítaseme dedicar ahora algunos minutos a otra faceta de la compleja relación entre medicina y valores humanos; me refiero a la ética médica que forma parte, por supuesto, de la bioética, que es el tema que hoy nos congrega.

El poder de la medicina se ha expandido en forma tal que las decisiones que toman los médicos tienen hoy un efecto como nunca antes lo habían tenido en la vida de las personas.

Como es natural, el trabajo del médico se ajusta a la evolución de la sociedad y la sociedad misma demanda cada vez más una ética sustentada en el principio que expresa el derecho inalienable de los individuos a la libertad.

El centro de la discusión está en el principio de la autonomía, el cual a su vez está indisolublemente ligado al de la autodeterminación; es decir, al fin y al cabo, es el paciente debidamente informado y en pleno uso de sus facultades quien debe decidir lo que es mejor para sí mismo.

El tema se vuelve más complejo si advertimos que otro signo del tiempo que vivimos es la creciente diversificación de los valores sociales.

En una sociedad plural y democrática es tan probable que los valores y los principios de los pacientes y la de los médicos coincidan como que discrepen; entre los propios médicos hay criterios distintos acerca de asuntos tan sensibles, como la eutanasia, el aborto, la prolongación de la vida, la sedación paliativa, etcétera. Pero no se trata sólo de ver cuáles son las preferencias personales del médico, aunque éste, desde luego, puede y debe dar su punto de vista.

Hay que entender que si estos asuntos no fueran polémicos y en no pocos casos también motivo de serios conflictos, la importancia de la ética médica sería bastante trivial.

Ahora bien, y aquí viene a mi juicio un punto central: si los polos del conflicto potencial se simplifican entre lo bueno y lo malo, corremos el riesgo de crear un conflicto moral insoluble.

En mi opinión, el tema debe abordarse desde una perspectiva estrictamente laica. En ningún ámbito de la esfera social, como en el de la medicina, hay una oportunidad más tangible para reivindicar al laicismo como la mejor forma de encontrar alternativas y soluciones ante problemas de interés general y cotidiano, desde la fertilización *in vitro*, el uso de células madre con fines terapéuticos, la prevención e interrupción del embarazo en ciertas condiciones, el cuidado de las personas que están próximas a morir, los nuevos alcances de la genómica, etcétera.

En el censo de población de 2010 se mostraron cifras preocupantes en México: fuimos 4 millones más de los que se suponía que éramos. ¿Qué pasó? Entre otras razones, la ideología se interpuso y los

programas de salud reproductiva se aflojaron en diversas entidades. Esto es simplemente inadmisible.

El análisis y la discusión de éstos y otros hechos, con información y con serenidad, va dando frutos, qué bueno, hoy tenemos este importante congreso en México.

Los cambios y los consensos toman tiempo y, sin embargo, tanto el teólogo como el humanista secular van encontrando puntos de convergencia en México y en casi todos los países democráticos.

Médicos y pacientes pueden o no tener creencias religiosas. Por eso insisto en que es precisamente el laicismo lo único que realmente garantiza que, así como no se puede impedir practicar religión alguna, ésta tampoco se puede imponer a nadie.

Lo que es un hecho es que si un médico priva a una persona de sus derechos, no está actuando en función de médico; si un médico le da la espalda a los enfermos, está renunciando al compromiso humanista de su profesión, deja a la medicina desprovista de los valores humanos que la dignifican y de la autoridad moral que requiere para su cabal ejercicio.

Son éstos algunos de los temas que he escogido para analizar, discutir, debatir en un espacio como el que hoy nos congrega. Hay que hacerlo con cuidado, con respeto, pero también con claridad y compromiso para poder informar a la sociedad con objetividad, con serenidad, con autoridad.

Tenemos una sociedad que acude a los médicos porque quiere saber más de asuntos que, por supuesto, le atañen y, en consecuencia, desea legítimamente opinar sobre ellos.

Dejemos, pues, que sean también nuestros pacientes quienes compartan con nosotros estas reflexiones, y conjuntamente tratar frente a los dilemas de encontrar las soluciones más éticas y que más se apeguen a los valores humanos.

d. Jonathan D. Moreno

Mind Wars: Brain Science and the Military in the 21st Century

What I'm going to talk about is not as important as many of the topics that people are discussing at this meeting. It is not as important as the

topics that we heard the previous speaker address; is not as pressing as problems of the poor and access to health care. Nonetheless, merging technologies have always been a concern for people in bioethics. I'm going to talk to you about neuroscience and emerging technologies with respect to research on the brain and their relationship to problems of national security and counter-intelligence. Not only as bioethicists, but also as global citizens, what's happening in the field of neuroscience is very important to us as the years go on. See if I can advance this.

We are now in the year of big neuroscience; the middle of the 20th century we had, of course, the era of big physics, we had the era of big genomics, the 1990's; we are now in the era of big neuroscience: lots of money, billions of dollars and euros invested and governmental projects of the highest level. The Human Brain Project, which is the European Union project, has as its goal to simulate the human brain in silicon, in a computer, within twenty years.

Those of you who are not able to think of an ethical issue that that might rise, you're not longer welcome at the bioethics meetings. Obviously, this already raises very interesting ethical problems. For example, at what point does a simulated brain become self-aware? It's an obvious question. Also, in the US, the President's Human Brain Initiative sets its goal to map the activity of neurons in the brain, using technologies, one of which, at least, I'll talk to you about.

I also have to give you this disclaimer: I'm not a member to the Commission, but I'm an advisor to the Commission, so what I say does not represent the views of the Commission, which is now drafting a report on ethical issues in neuroscience.

The science of the brain has undergone a terrific growth by any measure in the last twenty-five years. I just pulled some data of the web; it's simple, based on the growth of the number of papers published in neuroscience, the attendance at the meetings of the Society for Neuroscience now exceeds 40,000 people. It's a little bit more than we have here at the bioethics meetings. At least 40,000 attend these every year at the Society for Neuroscience. This has also spun off a lot of other organizations, for example, the International Neuroethics Society, a hardy 300 or so people, of which I had the pleasure to serve on the Board, and my University, the University of Pennsylvania, we

have a Neuroscience Boot Camp for lawyers and journalists and philosophers and others who are interested in the brain to teach them the basic fact about what's going on in neuroscience these days. There's a very vigorous discussion about the implications, and the lawyers in the room may know about the implications of neuroscience for the Law, and I will actually touch on that topic a little bit later on.

My special interest has been, for a number of years, the relationship of neuroscience to national security, and just taking some figures from funding for Cognitive Neuroscience, which is only a small part of the field of neuroscience, in the US Defense establishment, and these numbers are a few years old, but I can assure you that the investment continues. These are some figures that were collected by a colleague, Margaret Kosal, at Georgia Tech. DARPA, for those of you who don't know, stands for the Defense Advanced Research Projects Agency, which is the cutting-edge science agency for the Department of Defense, and the White House Brain Initiative has also said that DARPA should receive 50 million more dollars as part of the effort to understand more about the brain.

There's a prehistory to the conversation I'm going to engage with you that starts a really very long time ago, but I'll start arbitrarily in 1953. This was formerly a secret document, which was declassified in 1975. This document states that 39,500 dollars will be spent by the CIA on a project called MK-Ultra, which is project to understand the effect of LSD, a hallucinogen. LSD was formulated at Novartis in Switzerland, during World War II and the concern was that America prisoners of war during the Korean War were been given LSD and that they were being brainwashed, as the term went, and that they were being made to say treasonous things while they were being given LSD. This became a concern of the Central Intelligence Agency. Some of you might wonder what kinds of human experiments took place during this period and, in fact, some of the things that are going on were quite remarkable. We know, as a matter of record, that agents were going into bars and putting LSD in people's drink to see what would happen.

Were there any ethicists around? Actually, there were. Henry Beecher, as many of you know, wrote the most important paper in the history of American research ethics in 1966, disclosing what he regarded as highly unethical human experiments in the published

American Medical Literature. Beecher was an anesthesiologist at Harvard, who also was a CIA consultant on LSD, and used LSD in anesthesiology research at Massachusetts General Hospital in the 1950's; a very interesting figure. We shouldn't be anachronistic about this: everybody in science who was involved in areas that could be of interest to US national security in the Cold War was recruited for some kind of relationship with national security agencies.

This is a video that I think does speak for itself. It's about an incident that did take place at Porton Down in the UK in the early 1960's

Video: The drug was administered in a drink of water given at the start of each day's exercise. Twenty-five minutes later, the first effects of the drug became apparent. The men began to relax and to giggle, but this man was more seriously affected and had to be removed from the exercise. After thirty-five minutes, one of the radio operators had become incapable of using his set, and the efficiency of the rocket launcher team was also very impaired. Ten minutes later, the attacking section had lost all sense of urgency; notice the bunching and indecision as they enter a wood occupied by the enemy. Almost immediately, the Section Commander tried to use a map to find the location of the headquarters and the prisoner's escort had to have the way pointed out for him, although it was in plain sight 700 yards away over open country. Fifty minutes after taking the drug, radio communication had become difficult if not impossible, but the men were still capable of sustaining physical effort. However, constructive action was still attempted by those retaining a sense of responsibility in spite of physical limits, but one hour and ten minutes after taking the drug, with one man climbing a tree to feed the birds, the Troop Commander gave up, admitting that he could no longer control himself or his men. He himself then relaxed.

So these are British soldiers in an exercise to determine how the effects of LSD might be to disable a unit of soldiers. This was a matter of national security concern. I'm going to jump ahead, now, to the late 1980's, to the US National Research Council, a report on the mind race. I'm going to read this to you just because I love to read this. This was actually —you can look at this in the National Academy's Press website, "Enhancing Human Performance," 1988. "The claim for phenomenal applications presented by several multi officers ranged from the incredible to the outrageously incredible. The anti-missile time warp,

for example, is somehow supposed to deflect attack of nuclear warheads so that they would transcend time and explode on the ancient dinosaurs." Too much Star Trek viewing, I think, among these officers. "One suggested application is a conception of the First Earth Battalion, made up of warrior monks, including the use of ESP, extra sensory perception, leaving their bodies at will, levitating psychic healing and walking through walls."

I'm not sure these ESP experiments really worked all that well. Men, we've come a long way, so now I'm going to talk about the present day and I'll talk about a few drugs: one is modafinil, grand-marketed as Provigil, which is now being used by US Air Force pilots as a supplement, a replacement for speed amphetamines. Keeping people in the armed forces awake and alert in combat has been a problem for thousands of years: the Prussians tried cocaine as did Sigmund Freud, and just like everybody else at that time, in the late 19th century. Of course, there's caffeine, and nicotine and speed. Now, there's modafinil, which can keep you awake, according to the NIH for sixty to eighty hours, without any measurable loss of cognitive function.

There's been speculation about a brain hormone called oxytocin, which we make when we are having nice relaxing conversations. It sometimes is called the "cuddle drug" because apparently we seem to make it after a certain intimate interaction. There have been some experiments in controlled studies that suggested if you give people oxytocin through the nasal root and then you put them in competitive gaming situations, they will be more trusting and cooperative. This raises an interesting question, whether you can give oxytocin or something like it in an interrogation so that instead of torture, the next person coming in the room after you give the subject to the interrogation some oxytocin, would be the good cop; interesting ethical problems there.

It's been noticed by physicians for a long time that people who are on beta-blockers for heart disease seem to have a kind of leveling of their emotions. There's a notion that perhaps if you could give people beta-blockers before they go into, for example, a traumatic situation like combat, that you might be able to prevent the consolidation of the experience with an emotion like shame or regret or horror or fear. Would it be ethical, I'll simply leave this as a rhetorical question, to give war fighters before they go into combat something that could prevent

post-traumatic stress disorder, but which would mean that when they come back from combat as soldiers or war fighters who don't feel shame or guilt or sorrow about what they had to see or do in combat. I'll leave that question open.

Moving to some of the technology now, there's all kind of brain imaging; there's SPECT, there's PET, there's functional MRI, there's EEG, there's ultrasound. There's a company that markets something they call a brain finger printer that claims to be a lie detector. The FBI has actually bought some. I'm not sure I would endorse this product, but it is out there.

There are some remarkable experiments going on. I could have chosen any experiment from this week, there's always one. This is an experiment in which evoked brain activity allows the experimenters to reconstruct, using computers and functional magnetic resonant imaging, the image of a face, and that's the image of the face that they've reconstructed on the lower right-hand corner.

This is a group under Jack Allen at Berkeley. This is what you are looking like at in the functional MRI machine. This is the reconstruction of your brain activity, using data from functional MRI. Some really fast computers and some algorithms I will never understand. This is a laboratory reconstruction of what you are seeing when you are in the functional magnetic resonance imager. It's fuzzy; it's only the beginning. This is going just to get better and better and clearer and clearer. Not only the auditory cortex but also other parts of the brain are also being exposed in these ways.

Imagine that you are in an open brain surgery for say Parkinson's, you are going to hear a word in English and then you are going to hear two ways of reconstruction the word based on the neurons that have fired while you heard the word. So you're going to hear a word, then two different ways of computationally reconstructing the word.

For some reason, consonants are easier to reconstruct in these experiments than vowels but again, this is only moving in a certain direction. The Brain, Brain-Interface Experiment, you can read about it at the University of Seattle. I won't dwell on that one for reasons of time.

I'm not going to talk to you about the robot rat; basically, turning a rat into a robot. This was done at my former medical school with DARPA support in the mid 2000's about ten years ago. There are lots of rats

in Berkeley that you can turn into robots. This is an experiment that is trying to understand how lower brains actually process information. They can be turned into robots.

I want to end with a new technology, a thrilling new technology, transcranial direct-current stimulation which basically, or TMS, which basically sends a little electrical current into the brain. There's an old cartoon from a magazine in the US, "We have found by applying just the tiniest bit of an electric shock, tests scores have soared." It turns out that tests scores do soar.

There's an experiment, for example, that has stimulated neurons. In this experiment, people have seen a bush, for example, in the upper left-hand corner. When they are shown another bush on the right-hand corner after being exposed to these TDCS, they think it's the same bush; of course, it's not. Their neurons have been stimulated to recognize it even though they never saw it before: there's a big at-home hobby industry, do yourself TDCS. These are people who are zapping their brains, using an external device and then writing about it on a blog on the Internet. Just go to Google and look for blogs that say "TDCS" and you will find them.

I want to talk you finally about optogenetics. This is the newest technology out there that is really powerful. Basically, it's putting a light-sensitive protein called opsin into the brain, stimulating it with a fiber optic cable. When you turn the light on, you can push the proteins around the brain circuits and you can follow where they are going, because they are light sensitive.

I want to show you this little experiment that was done recently. It's called the Very Hungry Mouse. This is a mouse that is at the moment not interested in the popcorn. They turn the light on, stimulate certain neural pathways in the brain and it's quite hungry. It's instantly ravenous. You'll see that when they turn the light off and stop the opsin, the proteins from moving around in the brain that it's not interested in the food. When they turn the light on, it will be very hungry again.

This can be done for all kind of gross behaviors in the rodent and raises very interesting questions about the possibilities of using these kinds of technologies, for example, for patients who are suffering from eating disorders. What we will learn about the brain that will help us in the treatment of obesity or other eating disorders. This is basic science

that could go a long way. It also, however, raises very interesting questions, about how far you can go with higher primates with this kind of technology. I'm going to leave you with an experiment on the neuroscience of ethics. Here's an experiment that was done in MIT that I find very intriguing. How could you change somebody's ethical reasoning by exposing them to a little electrical impulse using transcranial direct current stimulation? I'll tell you what the experiment was. They brought in some white right-handed males who are undergraduates at MIT. They gave them a little moral test. What happens if your girlfriend were crossing what you knew was a dangerous bridge? Well, you'd stop her, right? You'd warn her. Why? Well, because we have a special relationship, I care about her and I don't want her to cross a dangerous bridge. Your loved one shouldn't be exposed to a possible harm. Then they give them a little zap and they ask them the same question, "Of course I would stop her." "Why?" Well, they gave a reasoning that was utilitarian instead of duty-based. I gave this talk in front of Peter Singer about a year ago and I said, "Peter, all those books you've written about utilitarianism, trying to convince your students, you don't need to do that. You just need to give them a little TDCS and you turn them into little utilitarians." I've tried to be a little light about this, but it's obviously a very serious business, because we are beginning to understand how to manipulate that which we think as the most human part of us, which is the brain. This presents powerful implications for bioethics in particular, but I think for our philosophical understanding of the mind-brain relationship in general. I look forward to talk to you about this more.

e. Amar Jesani

New Clinical Trials (CTS) Regulations in India: Bioethics Learns Through Engagement and Conflict

I must confess that I'm coming for the first time in a big international conference like this. I'm feeling pretty awed by the task that is... I think the first time in the speaking in the Plenary is very difficult task.

Before I go into what I want to say, I think what Professor Jonathan Moreno said just now reminded me of a big struggle in India, where the

techniques such as analysis and brain mapping, were used very frequently on thousands of detainees in order to interrogate them. The struggle of participation of doctors in this kind of testing of interrogation of detainees, meant for fighting with the Humans Rights Commission as well as filing cases in the Supreme Court in order to reverse the entire staff. Today, fortunately, the practices have stopped. Some people say that they have gone underground, rather than really stopped. But, to speak on this issue in a country like ours, despite being a democracy, is extremely difficult because you get branded as an antinational in our time.

Anyway, coming to the issue of clinical trials and all, is something that is based on my experiences. I'm not bioethicist by training. I come from the Human Rights movement to bioethics. I work more on the right to health issues. I believe that bioethics in the developing country cannot remain separate from the activism. I also believe that it has to become the advocate of the patients and the research participants. I am in a way biased because I have taken public stance on all these subjects and what I'm going to talk about here is not on a great theory, but my experiences from my work.

What I'm going to do is tell you something about clinical trial industry in India and the legal and regulatory framework. Along with that, I'm going to give you my own, you know, framework of presentation, what I believe that unless there is pressure from below, systems in the developing countries are very difficult to change. Bioethics, which is sitting in the academy and conducting research, is sometimes not adequate to really changing the situation.

As you know, India is undergoing a very high economic growth: there is a massive expansion of the private commercial sector, particularly pharmaceutical, hospitals and diagnostic industries. India is a big supplier of generic drugs in the world: almost 40% of the pharmaceutical production is exported. At the same time, the access to health care, including medicines within the country, is very poor: there are increasing inequalities, there's huge poverty as well as a large number of illiterate and semi-illiterate people. There is no universal access to health care and that raises a lot of questions about India being an exporter of drugs, while the people in India themselves remain without the access. At the same time, I must say, within the health

sector private industry prevails and there is very little regulations over them.

The legal and regulatory framework in India on the clinical trials in 2005 was much better. The Indian generic drug industry developed simply because of the kind of patent law it had: they did not provide patent for the product, but for the processes. There's a consequence: Indian industry was able to expand and come out with more generic products. That changed in 2003, when the product patents were accepted and the patents were provided for twenty years.

Drugs and technological research is regulated by law. Till 2005, India did not allow international clinical trial to take place unless they were already in the same phase in the country of origin. There a phase line for undertaking clinical trial in India, but amendments were made in 2005, when India decided that there should be further expansion of the clinical trial industry, and so in phase two and phase three of clinical trials, they started allowing the international simultaneous clinical trials in India.

The 2005 amendments also made mandatory plans, the online registration of clinical trials and the ethical review of the protocols. In a way, the whole system of ethical review was drafted into a system that did not have any regulations. Since several hospitals in India do not have to comply to any kind of quality standards in order to get registration, most hospitals in India are not registered still. A new law passed for the clinical trial establishment registration is still in the making. Suddenly, you get research coming up in settings where medical practice is completely deregulated. Ethics guidelines were also developed in 1980 by the Indian Council of Medical Research and updated in 2000 and 2006. They have the same standard of suppressing in a certain extent even better than the Helsinki Declaration but there are no legal debts.

But the big system and the kind of developments that took place, were the consequences. The number of clinical trials increased meaning business really went up; these were being carried out in all 4,000 institutions all over the country. The phenomenal increase in the number of institutions and common committees amounted to over 500 in 2011. Reports of lack of training of members, lack of independent and good functioning of the ethics committee and the force of the conflict of interest within the ethics committee started coming out

regularly. In May 2012, the 59th Parliamentary Committee Report documented irregularities among drug regulators and the clinical trials: the approval of the new drugs and exposing the nexus between companies and doctors.

What was very shocking to us was the way marketing for the clinical trials were done by the context research organizations in order to get contexts from the sources. Three major marketing devices were used: that the trials will be quick, they'll be cheap and would be easy. Because the population is large and a lot of vulnerable people are deprived of health care, they said that it would be very easy to recruit them for the clinical trials, since you'd be providing care free of charge. At the same time, the law, education and the resources made it also easy. If people were not at all being treated, what they'd say is that what you get out of patients, treating patients for whom you don't have to have any wash-out period. Of course, chief trials are easier to do it in India because prices are low and collaborators, such as doctors, and hospitals very much used to the business model, were easily available.

Soon after the control had started coming out, the main thing that started getting reported and that came out were injuries and death in the international clinical trials. It was found that in 2005 and 2012, in 75 clinical trials of new chemical entities, there were approximately 11,970 non-filed serious adverse events and 2,645 deaths; of them, only 89 were declared as causally related to the clinical trials and so, eligible for the compensation. They were provided a very pretense in the compensation, since there was no compensation for the injuries in the clinical trials.

At the same time, several other controls started hitting the headlines. Clinical trials on psychiatric patients, on survivors of the 1984 Bhopal valve-gas disasters, on the children in juvenile homes. There were several controversies regarding the testing for the carcinoma cervix as well as its prevention. One of the main ones was the Demonstration Project where in a phase of clinical trial there were no good system in order to follow because were given the HPV vaccine. Some six, seven deaths took place and there were no documentations to find out whether those deaths were related to clinical trials or not.

The letters when the tests come out is the visual inspection of subjects, the ascetic acid, where 180,000 women were not tested

because they were in the placebo-control variant. It is reported that some 254 women suffering of carcinoma cervix had died.

These controversies have really shocked up the bioethics world. This is my major point here: that we people in bioethics in India, for the last decade, have concentrated too much in collaborating with industry as well as with researchers. Much of the efforts are made by the bioethics-trained people in India, including myself. I'm not trained but at the same time, because of my own experience, I have been doing a lot of training in bioethics, so bioethics training for researchers and ethics committee members has been a major issue. Being a part of this committee and contributing in the ethics review has been one of the major work that we have been undertaking.

The bioethics people have been involved in formulating new guidelines but also efforts in some of the exposition that took place. I was evoked in several ethics committees and I found the whole structure extremely difficult to make any impact. The institution doesn't provide really good autonomy to the ethics committee. This is not as much focused on the patients, but they are more on defending the institution, and the system does not forbid the ethics committees to shop in the pharmaceutical companies and so on.

On the other hand, I've found that activists from the human rights organizations and NGOs took up the issue of injuries and the deaths in a very big way. Indian bioethics meetings bemoaned the problems of the system, but could not shake them. NGOs and human rights activists see the issue of death and injuries in clinical trial as a tough concern. They often do a lot by meeting a group of participants and by bringing media spotlight on the problem. So, the ethical system documented the cases, as well as the right use of the information law to force regulators administer to part with information, the petitions filed in the Supreme Court of Justice and the National Human Rights Commission. It was not the bioethics academy, but the human rights activists who posed the goal of coming out with new regulations.

There are major five components of the new regulations. I'm not going to go into all of them. The first one is treatment for the serious adverse events, independent assessment of the serious adverse events, the compensation for injuries and deaths, the registration of issues that were not there earlier, but they are tasked with the

monitoring of these so-called clinical trials and also undertaking a role in the assessment of the injuries. This has been given to those committees that are not functioning in any case. Mandatory audio-visual recording of the informed consent process has been brought in. Those things aren't enacted, they are still being reviewed and with a new government in office, we still don't know how it will go.

What is very important is that human rights activists were able to make a point on comprehensive and free medical management and treatment of all adverse events in clinical trials. In respect to the relatedness to the experimental drug or the intervention made for the city, this is the right of the patients on clinical trials. The independent assessment of the fatal SAE, and the relatedness to cities by the expert appointed by the drug regulator; this is, I think, an innovation that the human rights activists had pushed through in India. Most of the time it is the debt accepting monitoring boards, which are appointed by the pharmaceutical company, that makes decisions whether causality relationship of the SAE is with clinical trial or not.

The relatedness of the SAEs is not merely with the endorsements of the experimental drug but with the whole of the clinical trials. The injuries and deaths related to those eligible for monetary compensation, which is in addition to the treatment, and the formula for the monetary compensations, are being debated at the moment. There were seven criteria that came out with the relatedness which have become very controversial particularly the criteria CND, which says that the failure of the investigational product to provide the intended result and the use of placebo in the placebo-control trial, means that any serious adverse event coming up because of the failure of the investigational product or if placebo control is used, must be then compensated monetarily in addition to providing care.

Let me go to the final lessons. What I have learned is that bioethics training in research has long-term importance and is really essential, but the problems are here and now. We take a long time to create a new bioethics community and the regulatory system at the same time the business really expands in a big way. On its own training is unable to make system change. We also find that in developing countries it is very difficult to change the system from within; unless there is a strong political pressure from a mass movement, it is not possible to really

transform it. People in bioethics should build alliances with civil society dealing in human rights activism, because they achieve the goal of making research ethical. Within them, I don't think the ethics committee is a forum where this could be done. Patients' participative experiences need to be documented and they must form the foundation of research ethics. I think that is something that is missing and we must give more attention to that.

We need to reflect on the issue of vulnerability of participants in developing countries from two additional perspectives. One is that if vulnerability demands additional protections and investment to improve the context that could prevent exploitation, then how could research in the developing countries be so cheap and quick? Even if it is cheap, it can't be great. It should take longer time simply because you have to create something more. If you want to really have a genuine informed consent process or respect to autonomy, you require more time to make people understand rather than less time. In the entire process, there is no agency provided to the participants, patients and the participants. The strong scandals; they have no representation in the assessment of injuries and deaths and there is no representation in the compensation process. It is all done by experts, who may be bioethics or medical experts.

The causality relatedness of the injuries, as this process brought out, is really often defended as blocks, and it's already been drawn that there is no really a definite science, perfect science to find out the causality relationship. The onus of proving beyond doubt that they are not related to the clinical trial or beyond the researchers and the sponsors, should not be on the patient to find, to prove that he or she was injured by the clinical trial. Uncertainties in providing non-relatedness must favor the participants for compensation and not the sponsor. What we find is that only those deaths and injuries, where there is a definite relationship, is provided by the Data Safety Monitoring Board: they are provided compensation, but if it's probably related or possible related or there are uncertainties about the relatedness, no compensation is provided. I don't know why the benefit of doubt should be given to the industry and not to the patient who is the weakest link.

The causality assessment by a body not appointed by the sponsor is a must, because it is the only way of having a correct assessment. I

think it is also important in the context of the demand of transparency and openness of clinical trial data. When the researchers are able to reanalyze the clinical trial data and they find that the adverse events were not properly recorded or properly assessed, in that case, what happens to the patients who suffer? Who provides them compensation? More researchers are needed on the issue of causality assessment.

The issue of respect of autonomy is very difficult indeed in developing countries. It is difficult to provide primacy in the developing country setting. The context and the process demand radical improvements in order to make it official. They are very often very difficult to improve. Need for research and the recommendation of the kind of system that is conducive for the ethical research. I think we have learned that you require building of a whole system in order to allow the kind of commercial clinical trials that India started allowing since 2005. Without the system, if you open up the society for the common selectivity of this kind, then the consequences are not going to be good. ◗

3.4 Session 3

Chair: Inez de Beaufort
Maria Casado: *Ethics Committees: From Protector to Legitimizers*
Peter Kemp: *The Irreplaceable: A Fundamental Principle of Bioethics*
Juliana González: *Philosophical Perspectives on Bioethics*

a. Introduction

Bioethics fits into two simultaneous categories at least: *1*) a practical and applied field of study informing, among other things, ongoing ethics reviews and committees, and *2*) a theoretical field of studied informed by thousands of years of philosophy. Where does it emerge from, where is it going, and how is it impacting lives on a daily basis?

Ethics committees must grapple with abstract ideas, such as the notions of "autonomy" or "dignity" and apply them to real-world cases to achieve more just results in the conduct of science. Ethics committees are unique organizations, institutions built from perceived moral need, created by laws and regulations, consisting largely of volunteers from a variety of backgrounds, judging projects based upon philosophical principles that are at best only poorly defined, constantly debated, and in flux.

Professor Casado notes that even now, we are grappling with the proper and most effective form of ethical committee composition and oversight. Ethical committees are instruments created by law to provide proactive guidance before the conduct of a study, and to oversee (though less intrusively) the ongoing conduct of scientific research conducted on humans. They function under the assumption that there exist human rights that are consistent and applicable to all through application of various principles that can guide science. To what degree can a single culture's current and evolving views about ethics be translated into useful dialogue and decisions in a particular committee, made of members of scientific professions primarily, much less some general consensus viewpoints among diverse and geographically disparate committees? International organizations have long attempted to create guiding principles, to provide education, and to devise manners of disseminating opinions, procedures, and communication among ethics committees as forms of guidance. An international milieu complicates the picture.

Ethical norms change over time even within cultures. Over any geographically dispersed population, ethical norms also vary from place to place. Overseeing multi-population studies over periods of time, often occurring in differing jurisdictions poses legal and ethical questions that complicate the committees' roles. Can ethical values be sufficiently understood, much less instrumentalized, in useful and consistent ways by a single committee, across numerous committees, by committees in varied nations and with differing cultural backgrounds?

Perhaps bioethics is part of a broader ethic of cosmopolitanism: as Professor Kemp notes. This viewpoint recognizes that we are not isolated cultures and more than individuals within cultures are isolated individuals. We belong to a broader network of institutions, an

international agglomeration of societal norms and bodies whose collective actions and beliefs help to define the modern world. Underlying our cultural and individual norms are themes that represent common threads, including notions of dignity, autonomy, and respect, three basic principles applied commonly by bioethics committees and recognized by philosophers as foundational in a number of ethical systems. Moreover, we inhabit a planet together, and the realization of the interconnectedness of ecosystems with biological individuals, forces a new sort of cosmopolitan worldview, by which we are not only members of the human community, but of a biosphere, interconnected and interdependent. With this realization must come new perspectives on ethical duties beyond simple duties to family, neighbors, communities, etcetera. Rather, duties multiply and abound, and include duties to previously unconsidered inanimate elements of our environments. A cosmopolitan worldview helps not only describe the bases of various, well-recognized ethical duties and sources of rights, but also provides a foundation for a 21st century perspective on educating in bioethics, in a multicultural world, respecting differences but abiding also by some overarching principles.

The cosmopolitan ethic shares deep roots in Western philosophy, and strains of similar theory can be found in other parts of the world as well. From Aristotle, Socrates, Kant, and Lévinas to Buddhist and Taoist philosophy, the notion that we are all "citizens of the world" is consistent with principles we must employ in guiding scientific research. No one favored class, nationality, or role may prevail over some vulnerable individual or group, and we do not get to use others as means to ends. As free and equal world citizens, we are all entitled to the same basic level of dignity and respect. As many have noted throughout these presentations, the international nature of new forms of research collaborations demands that we adopt some form of cosmopolitanism if justice is to be served.

Finally, as Professor González notes, philosophical schools of ethics, long established and more recently employed through bioethics, must also grapple with new scientific knowledge. The study of DNA has shown not only that we are connected, for instance, by societies, cultures, laws, and norms, but also more fundamentally by a molecule. Our investigations of our genetic heritage, the neural bases for our

experiences and beliefs, and perhaps even the sources of our ethical judgments may all reveal to us a greater, more solid basis for decision-making. Meanwhile, we have a duty to pay attention, to continue to engage with scientists, philosophers, medical doctors, and others who are all investigating fundamental questions about the existence and experience of humankind.

The modern examination of bioethics is necessarily linked with the broad history of examination of humans at every level, just as mankind is not reducible to physical functioning, is not a group of automata following deterministic physical laws, so too must ethics take note of the sources of dualistic conceptions of man, even if they serve only as metaphors. The good is not found in any atom or cell, neuroscience and genetics cannot describe the "oughtness" of our actions and choices, but our common heritage as humans is also inextricably linked to our genetic and neurological makeups.

Bioethics is an evolving field, informed by numerous other areas of research, and encompassing a broad array of viewpoints, methods, and traditions. These speakers remind us of that, and offer a rich variety of viewpoints, distinct yet also inter-related, sharing common themes, and expressing that richness even as they cause us to reflect upon our own individual experiences, opinions, and biases. The field grows richer with each additional thinker who tackles these questions, both at the practical, ground level, and the theoretical birds-eye views expressed herein.

b. María Casado

Ethics Committees: From Protector to Legitimizers

Para esta presentación, aparte de un placer, siento una responsabilidad. Sinceramente cuando la preparé, lo primero que me preguntaba era: ¿qué decir en un foro mundial?, ¿qué tema elegir?, ¿qué enfoque? Porque tuvimos la generosidad de elegir sobre qué hablar, eso no siempre sucede, pero cuando sucede es doblemente interesante.

Entonces, decidí apostar por una cuestión puntual, por una cuestión muy concreta y por una no del todo políticamente correcta. Aquellos que me conocen ya saben que me gusta aprovechar los retos.

En realidad, creo que es importante señalar que mi concepto de bioética tiene mucho que ver con la reflexión, por supuesto, racional, argumentativa, y que es flexible, plural y tiene una base científica fuerte. Creo que son requisitos imprescindibles en la reflexión bioética. Pero la mirada que caracteriza a mi grupo, la enmarca en los derechos humanos reconocidos, y precisamente analizando no sólo las cuestiones meramente éticas, sino también las legales, las sociales y las políticas.

En ese sentido, hoy quería decirles que mi trabajo —que se ha centrado mucho en construir redes, en formar miembros para comités de ética— va a cuestionar qué está pasando con los comités de ética.

Como saben, los comités de ética son la forma de poner a la bioética en acción, de llevar a la práctica aquello que la reflexión y los marcos normativos establecen y las decisiones sociales y los contextos. ¿Pero qué está pasando? Creo precisamente que los Comités de Bioética son la bioética en acción, es verdad que los comités se están moviendo. La pregunta es: ¿hacia dónde? Se están transformando de una manera paulatina, y no estoy muy segura que sea en el sentido que todos deseamos, o no siempre.

Los comités de ética existen, en muy distintos ámbitos, pero en todos ellos deben ser mecanismos de protección de los ejercicios de las personas que están implicadas en aquellas cuestiones que los comités resuelven, que éstos evalúan, que éstos discuten, que los comités están tratando de analizar para encontrar ese equilibrio entre los riesgos, los beneficios, una ponderación de los intereses, de los derechos en juego, que garanticen efectivamente la protección de los derechos y las libertades.

Pero también creo que los comités tienen que ser instancias críticas que, en una sociedad como la que tenemos, son muy necesarias, y precisamente por eso, por las funciones que tienen, y también lo dice así la normativa.

Realmente la bioética y los comités de ética tienen un vínculo muy profundo, porque la relación entre derechos humanos y bioética, donde más se pone de manifiesto es en el trabajo de los comités. Esa bioética en acción se aprecia, en los comités donde se desarrolla, en los mecanismos de aplicación de la Declaración Universal sobre Bioética y Derechos Humanos de la UNESCO.

Se me ha presentado como titular en la Cátedra UNESCO de Barcelona de Bioética, y efectivamente una de las tareas que tenemos es la promoción y el cumplimiento, dar a conocer la Declaración Universal sobre Bioética y Derechos Humanos de la UNESCO.

En su Artículo 19, precisamente esta declaración se ocupa de los comités cuando habla de la aplicación de la Declaración, de los ámbitos de su aplicación, son los mecanismos aplicativos de lo que ésta establece.

Como ven, en el Artículo 19 de la Declaración Universal se dice que los comités deben crearse precisamente para promover, para apoyar al nivel que corresponda, comités plurales, pluridisciplinarios, independientes, y que eso deben hacerlo los Estados y las instituciones.

> Artículo 19 – Comités de ética.
> Se deberían crear, promover y apoyar, al nivel que corresponda, comités de ética independientes, pluridisciplinarios y pluralistas con miras a:
> a) evaluar los problemas éticos, jurídicos, científicos y sociales pertinentes suscitados por los proyectos de investigación relativos a los seres humanos (comités de ética en investigación);
> b) prestar asesoramiento sobre problemas éticos en contextos clínicos (comités de ética asistencial);
> c) evaluar los adelantos de la ciencia y la tecnología, formular recomendaciones y contribuir a la preparación de orientaciones sobre las cuestiones que entren en el ámbito de la presente Declaración (comités nacionales de ética o bioética); y
> d) fomentar el debate, la educación y la sensibilización del público sobre la bioética, así como su participación al respecto (la educación en materia de bioética, involucrar a la sociedad en materia de bioética, debate social).
> UNESCO. *Declaración universal sobre Bioética y Derechos Humanos*. 19 de octubre de 2005.

He hecho una breve referencia a cuáles son los principales cometidos de los comités. Efectivamente, evaluar problemas éticos y jurídicos, como suele suceder en los comités de investigación, temas que afectan

a seres humanos, prestar asesoramiento sobre los problemas éticos en contextos clínicos, como hacen en general los comités de ética asistencial, evaluar los adelantos a la ciencia, asesorar a las altas instancias legislativas, al gobierno, a la administración, como hacen los comités nacionales, y fomentar el debate. A mí eso me sigue pareciendo de las cosas más importantes. Creo que los comités tienen un compromiso con los ciudadanos, deben tenerlo. Y eso es parte de esa tarea educativa, de esa tarea de sensibilización que deben tener y deben llevar a cabo los comités, como participación en ese debate social. Es algo verdaderamente importante.

Pero me pregunto: ¿los comités deberían ser así? La pregunta es: ¿lo son? Ahora voy a ponerles una serie de ejemplos. Vamos a ver qué está pasando, y voy a ponerles de manifiesto una visión crítica de algunas de las cuestiones; y como eso es políticamente incorrecto, voy a tomar algunos ejemplos, el primero lo voy a tomar de mi país, de lo que conozco, pero pondré muchos otros, porque éste es un ejemplo, pero muchos hay.

Realmente hemos perdido de vista cuáles son los objetivos. Hay mucha buena voluntad, mucha buena fe en los comités, pero no siempre, a la hora de la verdad, suceden las cosas como estaban previstas.

El Comité de Bioética de España, creado por la Ley de Investigación Biomédica (*BOE*, 4 de julio) en 2007, es un "órgano colegiado, independiente, de carácter constructivo, que desarrollará sus funciones con plena transparencia sobre las materias relacionadas con las implicaciones éticas y sociales de la Biomedicina, y las Ciencias de la Salud". Eso es lo que dice la Ley: transparencia, independencia, carácter consultivo.

> La Misión del Comité de Bioética de España, es emitir informes, propuestas y recomendaciones para los poderes públicos de ámbito estatal y autonómico sobre materias relacionadas con las implicaciones éticas y sociales de la Biomedicina y Ciencias de la Salud. Asimismo, se le asignan las funciones de establecer los principios generales para la elaboración de códigos de buenas prácticas de investigación científica y la de representar a España en los foros y organismos supranacionales e internacionales implicados en la bioética.

Yo fui miembro de este comité en su primera composición. El comité empezó a funcionar en 2008, y a los cuatro años tenía que renovarse la mitad, por sorteo, lo que no sucedió. El comité cambió su composición por decisión del gobierno.

Tenemos dos informes sobre un tema sensible y delicado: en un comité que empieza a funcionar en 2008 no deja de ser curioso que haya un informe de 2009[1] y otro de 2014[2] sobre el mismo tema: la interrupción voluntaria del embarazo.

En el primer informe en el de 2009, cuando yo era miembro del comité, y del que puedo hablar, se avalaba la opción legal hoy vigente en España, que es un sistema legislativo que mezcla el plazo con las indicaciones, en función de los criterios habituales de capacidad de decisión de la mujer y de protección del feto conforme aumenta la viabilidad.

Esa Ley no daba ningún problema en nuestro país; ha estado desarrollándose y sigue hasta hoy, pero el gobierno actualmente ha hecho una propuesta, un proyecto de ley, que ha sido evaluado en ese otro informe de 2014.

El problema es que si en tan poco tiempo una alta instancia nacional puede cambiar de manera tan radical de opinión. Claro que la composición es otra, se renovó íntegramente, cosa que tampoco es habitual: los comités se renuevan por partes.

¿Qué quiero decir con eso? Que, de alguna manera, me parece que pone de manifiesto de forma clara que a veces los comités pueden tomar decisiones de carácter político, tentaciones, del poder de hacer los comités a la medida.

Sinceramente, en muchos lugares es así, pero también hay grados, hay comités con una trayectoria magnífica, que conocemos, que son un ejemplo, que toman su composición; la imagen con la semejanza a lo que es el contexto social para el que actúan.

1 Opinion of the Spanish Bioethics Committee in Relation to the Voluntary Interruption of Pregnancy in the Draft Organic Law 2009; http://www.comitedebioetica.es/documentacion/docs/en/voluntary-interruption-of-pregnancy-oct-2009.pdf.

2 Report on the Law Proposal for the Protection of the Unborn and Rights of Pregnant Women (only available in Spanish) 2014; http://www.comitedebioetica.es/documentacion/docs/Informe%20Anteproyecto%20LO%20Proteccion%20Concebido.pdf.

Otras instancias de decisión que los forman carecen quizás de esa visión a largo plazo o de generosidad, y los conforman a la medida. Claro, los gobiernos se alternan en poco plazo; esa visión corta creo que es un muy grave problema. Creo que eso deslegitima y demuestra poco sentido institucional, pero la verdad es que sucede.

Hay más ejemplos. Muchos problemas tienen que ver con otros tipos de comités: los comités de ética de la investigación, los comités *ad hoc* creados para tratar problemas de investigación biomédica, de reproducción asistida, etcétera. Todos estos comités están hoy con problemas graves.

¿Cuáles son y cómo podemos resolverlos? Eso es lo que querría hablar con ustedes.

Me parece que quizás hay un *lado oscuro* en los comités. Me parece que para quienes hayan participado en algún tipo de comité —por ejemplo, uno que evalúe ensayos clínicos, que son los más característicos, o de investigación, los más clásicos—, yo creo que hoy día está pasando una cosa.

La primera es que en la forma de proceder del comité, sin ningún tipo de mala fe, están sucediendo hechos que alteran su misión. Para empezar: el procedimiento; no hay procedimientos de trabajos claros, transparentes; muchas veces los hay, pero están en el cajón. No se sabe bien si no interesa cumplirlos, tampoco hay una buena conexión entre los comités del mismo país o de la misma zona, a veces según qué comité; las decisiones son diversas, y eso ya sabemos nos lleva al mercadeo de comités. Vamos a llevarlo al comité que pensamos puede ser más favorable.

Creo que en estas cosas hay que estar sobre aviso, porque si nosotros hemos concebido los comités como instancias críticas, no podemos evitar, no podemos caer en dejar que los comités se conviertan en instancias dóciles.

A veces hay convocatorias absolutamente ininteligibles, tan cargadas de temas, que sabemos que no se van a poder tocar, tan cargadas y en las que los temas más importantes van al final, por lo que no vamos a llegar a ellos. Sin posibilidad tampoco de que después los miembros externos accedan, muchas veces a la información previa con el tiempo suficiente para evaluarlo, llega a los consentimientos informados, los proyectos en montón, y con muy pocos días para

evaluarlos. Muchas veces, además, se mandan aplicativos completamente, poco amigables, difíciles de manejar; llega tarde la documentación, los protocolos no contemplan muchas veces que se esté trabajando con información sensible; se manda información por correo electrónico, con lo que eso luego es de peligro para ser reenviado; y luego el tiempo entre las sesiones muchas veces es muy largo.

¿Y qué pasa entre una y otra? ¿Quién decide? Decide la Comisión Permanente. ¿Y qué es la Comisión Permanente? En algunos casos está muy claro, está perfectamente explicado qué es la Comisión Permanente, pero en otros no. Ése es el lado obscuro de los comités. También hay cuestiones que tienen que ver con qué es trabajo voluntario. Creo que debemos plantearnos esto. Los recursos humanos y económicos, el soporte de la institución, ¿el trabajo de los miembros debe ser pagado?, ¿debe ser gratuito?, todas estas cuestiones las tenemos sobre la mesa en todos nuestros países.

Entonces, yo quería aprovechar la influencia del mercado. Aprobemos muchos protocolos. Mientras más ensayos hagamos, más fondos entran a la institución. Somos inocentes, ingenuos o excesivamente confiados si no somos capaces de ver que estas cosas pasan. Los comités deben ser eficientes y revisar muchos comités, o revisarlos con mucho cuidado. Hacer cinco al año o hacer 480 o 710 —como hacen muchos hospitales de mi contexto—, mil incluso; la influencia de la industria, la influencia de la crisis a la búsqueda de fondos; la verdad es que todo esto es muy complicado. Si no nos sentamos a ver cómo, además de aprobar, hacemos después el seguimiento. ¿Se hace el seguimiento de los comités? Pienso que no.

Por otra parte, éstas han sido denominadas muchas veces cuestiones de biopolítica, y lo son, porque realmente con meras y buenas intenciones no vamos a llegar a ningún lado. El discurso bioético melifluo, de "qué buenos somos y queremos ser", necesita el "diga cómo". Que queremos hacerlo bien, lo sabemos, pero diga cómo, y para eso, por ejemplo, los comités necesitan que sus miembros estén formados; necesitamos una formación específica, porque los problemas son grandes y las discusiones que están debajo son muy importantes.

En conclusión, los problemas que en los comités estaban iniciándose, que se veían desde el principio que podíamos llegar a tener, hoy día

están presentes, que pugnan por aparecer, que pugnan por tenernos atrapados con ellas.

Eso era lo que hoy en una sesión como esta, con 1,200 personas preocupadas por los problemas, he querido poner con ustedes en común. Para mí es un reto pensar que las cuestiones hemos de solventarlas, no simplemente alegrarnos de la gran bondad que supone trabajar cuestiones bioéticas por el bien de la humanidad.

c. Peter Kemp

The Irreplaceable: A Fundamental Principle of Bioethics

I will speak about two things that have occupied me very much in the last years. I have published a book recently about the citizen of the world first published in Danish and then translated into English. Some years ago I published a book in Danish, German and French about the irreplaceable. I'll try to show the connection between these two ideas, irreplaceable and bioethics.

If ethics is care about the good life, and if we understand bioethics as a kind of ethics that focuses on care about life confronted with today's advanced technology, and if we define cosmopolitanism in our time as a kind of care about the life of humanity confronted with the global burning issues of today, bioethics can be understood as belonging to cosmopolitanism.

In my work on the *Citizen of the World*, published in Danish in 2005 and in English in 2011, I have mentioned three burning issues of our time:

First, the problem of *financial globalization*. The financial crisis in 2008 showed that we need a democratically controlled world economy.

Second, the problem of *intercultural coexistence*. Conflicts and wars between different cultures show that a reconciliation between cultures —for instance, between Islamic and Judeo-Christian cultures— is strongly needed.

Third, the problem of *the physical sustainability of the earth*. This is the global problem on which bioethics must focus, since it has to care about living beings challenged by the consequences for humanity

of using advanced technology. Human beings are not only increasingly exhausting some of our most accessible but non-renewable resources without being able to replace them with renewable resources, but they are also using production methods that might destroy the natural conditions for human life without enabling us to restore them. We might, therefore, leave future generations a world with inferior material conditions to those we know —in particular, a world plagued by anthropogenic global warming. We need to exercise more responsibility towards the earth, so that people in a future world will not blame us for our exploitation of physical capital and the destruction of the world's climate.

Bioethics is also concerned about the fourth problem, which is linked to all three global problems, i.e., the problem of how to fight transnational criminality.

But if bioethics today must be an aspect of cosmopolitanism to grapple with and offer solutions to the burning issues of our time, and if this cosmopolitanism, therefore, is a superior idea that encompasses all aspects of care about the world, bioethics is superior to cosmopolitanism in that bioethical reflection can most clearly express the fundamental normative principles of care about the whole world.

Cosmopolitanism, very broadly defined, is a concern about global citizenship. The citizen of the world believes that national citizenship must imply living together with other kinds of national citizenship and must thereby recognize a global citizenship. The global problems that the humanity faces today have made it necessary to accept a higher idea of sovereignty than the idea of the sovereignty of the nation-State —not in order to abolish the sovereignty of any particular State but in order to recognize a dual citizenship for every human being, that of the citizen of the State and the citizen of the world. This was the very abstract cosmopolitan idea of the Stoics two thousand years ago, but it is now becoming politically concrete.

Now, the question arises: what is the fundamental principle of this cosmopolitism? This question has recently been discussed by French philosophers; and, in his last two books, a professor in philosophy at the Sorbonne Yves Charles Zarka has proclaimed the idea of the non-appropriability of the earth as a founding principle of cosmopolitism today. He argues that, in our time, the appropriation of the earth is

unacceptable both from an ethical point of view and from a legal point of view, since it is the common dwelling of all human beings.[3]

I will not deny that the idea of the non-appropriability of the earth must be an important normative idea of cosmopolitanism today, but it seems to me that cosmopolitanism cannot be limited to a denial of the right to unlimited appropriation and domination of the earth, which is common to all human beings. My question is: Doesn't bioethical reflection dig deeper by looking for an even more fundamental principle that expresses care about life on earth, whether it is economic, cultural or biological and existential life?

In order to answer this question, we must first clarify why care of living beings is a primary demand in our time. In earlier times, ethics was only about concern for the other human being. It was only about good personal relationships. But ethics has been enlarged to include bioethics because medical treatment and biotechnology make possible all kinds of biochemical and technical interventions in living organisms in general and in human beings in particular.

Thus, this enlarged concept of bioethics extends from the ethics of the relationship between patient and health professional to the ethics of care for animals and for the whole of nature. Bioethics concerns our entire *life-world* insofar as its ethical judgments are relevant to biomedicine, our treatment of animals, and our conduct in relationship to the ecosphere as such. It is intimately connected to an understanding of the good life with the Other —both the other person and the nature in which we live and for which we are responsible. Just as I must show my respect for another person for his or her own sake, I must show my respect for nature for its own sake, recognizing it as just as irreplaceable as the persons who constitute the conditions of and an enrichment of my life.

This indicates the fundamental principles of bioethics. It is the irreplaceability of the human being and of living nature. This irreplaceability constitutes an appeal to our care and our responsibility.

The German philosopher Hans Jonas claims in his book *The Imperative of Responsibility* that "modern technology has introduced actions of such novel scale, objects, and consequences that the

3 Yves Charles Zarka: *L'inappropriabilité de la Terre*, Armand Colin, Paris, 2013, and *Refonder le cosmopolitisme*, PUP, Paris, 2014.

framework of former ethics can no longer contain them."[4] The prescriptions of "neighbor" ethics still hold in their intimate immediacy, but "this sphere is overshadowed by a growing realm of collective action where doer, deed and effect are no longer the same as they were in the proximate sphere, and which by the enormity of its powers forces upon ethics a new dimension of responsibility never dreamed of before."[5]

This new ethics implies, according to Jonas, three new elements of responsibility in that *1*) nature has become so vulnerable to human intervention that we are no longer sure that it will subsist independently of the way we treat it, *2*) knowledge about the technological means of action has become the prime duty beyond anything claimed for it before because, today, we must "consider the global condition of human life and the far-off future, even existence, of the race,"[6] and *3*) the "anthropocentric confinement of former ethics no longer holds."[7]

The recognition of this new dimension of responsibility not only changes our ethics but also the scope of cosmopolitanism. Jonas wrote his book on the principle of responsibility as an antithesis to the work of Ernst Bloch in *The Principle of Hope*.[8] He refused to interpret responsibility in the light of a utopia of an ideal world; he wanted to understand it according to the new conditions of life today. Nevertheless, the responsibility of which he speaks implies a cosmopolitan vision of a world that is not yet realized since the major problems he cares about are not yet solved; he mentioned the problems of food and mineral supply and the energy problem, including the thermal pollution that is called the global warming today.[9] But if these problems are not yet solved, the world in which it is the case does not yet exist; and, therefore, the citizen of the world who is responsible today cannot avoid utopia.

Whereas Jonas has connected the concept of responsibility to what the Japanese philosopher Tomonobu Imamichi has called from

4 Hans Jonas: *The Imperative of Responsibility. In Search of an Ethics for the Technological Age* (1979), The University of Chicago Press, Chicago and London, 1984, p. 6.
5 *Idem*.
6 *Idem*, p. 8.
7 *Idem*.
8 Ernst Bloch: *Das Prinzip Hoffnung* (1938–1947), Bande I-III. Suhrkamp Verlag, Frankfurt am Main, 1959, English translation: *The Principle of Hope*, MIT Press, 1986.
9 *The Imperative of Responsibility*, p. 190.

an eco-ethical perspective the "the technological conjuncture" of our world today,[10] the French philosopher Emmanuel Lévinas has improved our understanding of responsibility by taking into account the barbarity of the Holocaust in the 20th century. Lévinas speaks about the face of the Other that calls my freedom "to responsibility and founds it."[11]

If we now unify the two concepts of responsibility —that of Jonas and that of Lévinas, we cannot limit the concept of the Other to the person we encounter face-to-face, but we must extend it to include not only individuals in the future but also nature, the earth or the world that is the condition of life and existence. That is what Yves Charles Zarka has done; he declares: "The Stoics spoke about the 'community of men and gods'. We prefer to say: the common city of humans and all living beings, given to human responsibility."[12] We can even say that the earth, as a living being, is irreplaceable: if we destroy it, we do not have another world that might replace it.

When Zarka claims that the appropriation of the earth is unacceptable, he refers to the destructive consequences that the idea of global land appropriation has from the moment it is linked to the widespread idea of human beings as "masters and possessors of nature" (as Descartes put it in his *Discourse on Method*).[13] Therefore, it is important for him to presuppose the idea of the non-appropriability of the earth and to understand by "earth" not only the vulnerable nature of which Jonas has spoken but also the multicultural humanity that is the concern in, for instance, the recent works of Martha C. Nussbaum and Mireille Delmas-Marty.[14]

10 Peter Kemp: "The Formation of the Idea of Eco-ethics" in *Eco-ethica,* Special Issue for The XXIII World Congress of Philosophy in Athens, August 2013, *Introduction to Eco-ethics III*, edited by Peter Kemp and Noriko Hashimoto, Tomonobu Imamichi, Institute for Eco-ethica, Copenhagen, Tokyo, 2013, p. 1.

11 Emmanuel Lévinas: *Totality and Infinity*, translated by Alphonso Lingis, M. Nijhoff, The Hague, 1979, p. 203.

12 *Refonder le cosmopolitisme*, p. 7.

13 René Descartes: *Discours de la méthode*, *Œuvres*, v. I, Joseph Gibert, Paris, Part 6, p. 61.

14 Martha C. Nussbaum: *Cultivating Humanity. A Classical Defense of Reform in Liberal Education*, Harvard University Press, Cambridge, Mass., 1997; Mireille Delmas-Marty: *Les forces imaginantes du droit,* Vol. IV, *Vers une communauté de valeurs?,* Editions du Seuil, Paris 2011.

Thus, we must admit "a cosmopolitan responsibility" that, as Zarka claims, would serve as a "regulatory principle of actions whether they are private or public, individual or collective."[15] And he is right when he claims that this principle must be grounded on the experience of a pre-original relationship that is our "belonging to the Earth, which is before every perception, every thought and every action and, at the same time, a condition of perception, thought and action."[16] Thus, the idea of belonging replaces the idea of acquisition or appropriation.

Truly, according to Zarka, the principle of the non-appropriability of the earth "does not oppose the existence of property as such, and it does not deny the frontiers of states," but it prescribes an imperative for the whole world "which end would be the preservation of the Earth as the ground of the existence of humanity and the whole living world."[17]

However, it must be recognized that the principle of the non-appropriability of the Earth must be rooted in an experience and a conviction that our earth, like the Other in personal relationships, is irreplaceable. Just as the Other must be protected in the personal encounter because, if I lose him or her, this person is irreplaceable for me, it is also necessary to take care of our world, of our cosmos, and consider the cosmos as the Other, because it can perish or become irretrievably unlivable —perhaps, not in our lifetime but for future generations. Truly, from a general human point of view, an individual animal can often be replaced; but, from the same point of view, every species is irreplaceable, since it belongs to the richness of life, and the whole living globe is more irreplaceable than every other being since it is the absolute condition of human life on earth.

The idea of the irreplaceable has deep roots in our culture.

First of all, it presupposes that the human being needs a community. In Aristotle (384-322 B.C.), the good life has to do with the right relation to other human beings, with our actions toward them, with our reactions to their actions, with our cooperation with them. It has to do with care of others. Therefore, to Aristotle, ethics is not only a question of the good life in friendships but also of the good in social

15 Yves Charles Zarka: *L'inappropriabilité de la Terre,* Armand Colin, Paris, 2013, p. 46.
16 *Idem*, p. 47.
17 *Idem*, p. 48.

organizations, in government, in politics. His *Nicomachean Ethics* is a kind of introduction to his work on *Politics*.

In Judaism, too, before the emergence of Christianity, ethics was a question of the formation of society. The Ten Commandments were originally rules for social life. But, with Christianity, a radicalization of ethics occurred when Jesus introduced the idea of the absolute value of the human individual. This makes ethics something more radical than social norms, which order the external relationships between people.

It is this radical thought that is expressed by the idea of the individual human being's irreplaceability. Philosophically, detached from traditional theological language, this idea was first seriously propounded in 1785 by Immanuel Kant in his book on *Groundwork of the Metaphysics of Morals*, which claimed that the main idea in practical philosophy was that a human being must act in such a way that, at any time, he respects the human person as an end in himself and never merely as a means.[18] It is true that we all treat each other as means to our ends, as we derive benefit from each other in order to achieve what we want. But if we treat others purely and simply as means to our ends, they have been reduced to nothing but material for our actions. Then, we are not regarding them as ends in themselves.

In that case, according to Kant, they have no dignity. And what has dignity has "no equivalent,"[19] i.e., it is irreplaceable.

Thus, in Kant, the idea of irreplaceability becomes the fundamental principle of his ethics. It is tantamount to the idea that every human being is unique. And, in accordance with Kant, this will not be the case if such uniqueness is understood biologically (in the sense that each has his or her own DNA formula) because the uniqueness in question here is existential. Human twins having the same genetic code are not identical existentially. If one of them dies, the loss is irreparable. He or she cannot simply be replaced by another being with the same DNA code.

Today, it is this idea of irreplaceability we can adopt as the fundamental principle in every bioethical reflection on the protection of the human being and of the whole living world that constitutes our life-world.

18 Immanuel Kant: *Groundwork of the Metaphysics of Moral*, translated by Mary Gregor, Cambridge Texts in the History of Philosophy, Cambridge Univ. Press, 1997, p. 38, Akademieausgabe, Bd. IV, p. 429.

19 *Idem*, p. 42; Akad.ausg. Bd. IV, p. 434.

Thus, bioethics offers to cosmopolitanism a more fundamental principle than the idea of the non-appropriability of the earth. It shows that, fundamentally, the citizen of the world —whether he or she is concerned with financial, cultural or ethical co-existence— has to adopt the idea of irreplaceability, both of the human individual in society and of the nature that sustains that individual's existence.

d. Juliana González:
Philosophical Perspectives on Bioethics

Gracias a los organizadores de este importante evento y que sea en México donde nos venimos ocupando de la bioética desde algunos años atrás. Pero creo que este acontecimiento le da un aire, una visión y una riqueza a la comprensión de los asuntos bioéticos que verdaderamente vale la pena aplaudir, particularmente a quienes han organizado este congreso.

Yo hablaré desde una perspectiva más cercana, desde luego, a la de Peter Kemp, pero quizás con una perspectiva un poco más orientada hacia los aspectos ontológicos de la filosofía.

Si hay alguna cita recurrente de Immanuel Kant, en el ámbito de la ética, y diríamos también en el de la bioética hoy, es aquella en que el filósofo hace el conocidísimo encadenamiento de preguntas: "qué debo hacer, qué puedo hacer, qué puedo esperar y qué es el hombre", encadenamiento que revela ciertamente el carácter de fundamento que tiene la última interrogante: ¿qué es el hombre?, pregunta de índole teórica cognoscitiva, base implícita de las tres primeras, eminentemente prácticas.

Hay varios indicios de que en su extraordinario desarrollo mundial y pluridisciplinario, en apenas cuatro o cinco decenios de vida, la bioética se ha desplegado preferentemente en las cuestiones de orden práctico, en aquellas, sobre todo, que han sido suscitadas por las revoluciones tecno-científicas de la biología contemporánea.

Aunque es cierto que no sólo éstas son causa del surgimiento de la bioética y de su crecimiento, hay otros factores sociales, históricos, culturales en general, que explican su nacimiento; los nuevos hallazgos

en las ciencias de la vida y sus imponentes capacidades tecnológicas han venido a alterar, a mi modo de ver, no sólo el campo de praxis médica, sino que conllevan una importante cantidad de saberes y poderes, capaces de alterar de raíz, para bien o para mal, la realidad misma de la vida humana y no humana.

De ahí la necesidad de un resurgimiento específico de la ética, con el objeto de atender a valores y principios fundamentales de la acción, así como la urgencia del derecho, como se demuestra con los derechos humanos, capaz de establecer criterios e instrumentos jurídicos para definir la validez de las acciones emanadas de las biociencias y las biotecnologías.

La ética filosófica, sin embargo, particularmente en su alcance ontológico, atiende ante todo, al aspecto cognoscitivo de las ciencias de la vida, a la cuestión última de las preguntas kantianas: ¿qué es el hombre? Se centra en especial en los descubrimientos teóricos que han traído consigo señaladamente la genómica y la neurobiología decisivos para el conocimiento de eso que se llama naturaleza humana.

Ésta sería la vertiente de la bioética que examina a fondo el impacto y la trascendencia de los nuevos conocimientos biológicos para la comprensión filosófica de la vida humana y la vida en general, y desde ahí, desde estos conocimientos, dar luces para definir cuáles son los criterios éticos, jurídicos, racionales y humanísticos que orientan las aplicaciones prácticas.

Desde una perspectiva filosófica, puede recordarse que el concepto de naturaleza corresponde a la palabra *physis* en griego, y ambas, *physis* y naturaleza, tienen, por una parte, la significación de lo que entendemos por naturaleza natural, física o biológica, y, por la otra, en griego y en español, también en latín y en inglés, adquieren el significado de la naturaleza intrínseca y esencial de lo que existe.

Pero esta dualidad de significados de *physis* o naturaleza se va a consolidar en la tradición filosófica por siglos y milenios como un dualismo tajante, como división antitética y excluyente entre lo que es la naturaleza natural, material, corpóreo, que priva en el mundo, espacio temporal, el cuerpo humano de manera muy destacada, y la naturaleza esencial, el verdadero ser incorpóreo e inmaterial, literalmente metafísico, al que corresponde el alma humana.

La milenaria concepción dualista no sólo domina en la tradición religiosa-ideológica de Occidente, sino también en el pensamiento filosófico, rigurosamente filosófico, desde Parménides y Platón, hasta en las más diversas corrientes de la filosofía de nuestro tiempo, pasando por el gran dualismo de la modernidad, representado por Renato Descartes.

Pero son justamente los dualismos, particularmente entre alma y cuerpo humano, los que con todo y sus variantes, son puestos en tela de juicio por las actuales revoluciones de las ciencias de la vida.

Son éstas las que paso a paso disuelven la diferencia y la dicotomía entre las dos *physis*, entre la naturaleza natural física y biológica, y la naturaleza inmaterial y esencial, lo cual es, en efecto, equivalente a que se disuelva la separación entre cuerpo y alma, o entre materia y espíritu, con todo cuanto éstos significan, pues lo que las biociencias traen consigo es un novísimo saber de la vida corporal, la cual es descubierta en unas profundas dimensiones suyas, hasta ahora desconocidas, reveladoras de un orden, de unas propiedades y unos poderes verdaderamente sorprendentes, sobre todo por su posible semejanza con lo que antes se había pensado eran las facultades del alma o el espíritu. ¿Es que el alma se halla en el micro espacio profundo de las células, de los genes y las neuronas?

La ciencia genómica y la neurobiología representan, en efecto, el descubrimiento de esa nueva dimensión físico-química, de esa especie de nuevo continente ultramicroscópico inherente a los cuerpos de todos los seres vivos.

Recordemos en un resumen muy breve y simplista que cuando se dio el hallazgo de ese singular ácido, el ADN, configurado como una doble hélice, se consideró que era tal su importancia que los descubridores exclamaron de inmediato: "Hemos descubierto el secreto de la vida, el ADN es la base invisible, eterna y fundamental de la identidad humana".

Este ácido explica nuestro sitio en nuestra historia, nuestra conducta, nuestra moralidad y destino. El ADN ha adquirido muchos de los poderes otorgados antes al alma inmortal.

Los cambios en la manera de comprender la naturaleza biológica han producido, en todo caso, eso que afirma Peter Singer: "el derrumbe de nuestra ética tradicional, obligándonos a repensar la vida y la muerte".

En efecto, en esa diminuta y a la vez larguísima hebra helicoidal, envuelta en el núcleo de cada célula, en esa perfecta secuencia de genes hechos de materia físico-química, se halla escrita con sólo tres letras: la naturaleza de cada especie viva, de cada grupo humano racial o poblacional y de cada persona en su irrepetible e irremplazable, como sabe bien Peter Kemp, individualidad.

Como un efectivo lenguaje, los genes se ordenan y reordenan entre sí, transmiten o transcriben por medio del ARN la información genética a las proteínas, las cuales son los cimientos de la vida, la doble hélice; en suma, se desdobla para transmitir la información, asegurando la reproducción y la pervivencia de todos los seres vivos a través de esos mensajes genéticos, en los cuales se condensan, en definitiva, nuestra naturaleza propia, nuestra identidad y nuestro destino vital.

No sólo esto; el genoma, particularmente el del ser humano, delega en el cerebro la capacidad de hacer experiencia, de ser modificado por la realidad externa e interna, siendo la plasticidad su característica principal.

Visto desde una perspectiva tan general como abstracta, cabe destacar al menos el hecho de que, como se sabe, el cerebro está constituido por células excepcionales, las neuronas. Consta de dos hemisferios izquierdo y derecho, y tres partes en general o regiones de carácter general: tronco, hipocampo, neocortex, que todo configura una masa, la masa encefálica, singularísima, materia viva, la cual, vista de cerca y por dentro, constituye un verdadero universo cuantitativo y cualitativamente extraordinario, donde todo, como diría el buen Leibniz, está relacionado con todo.

Cuantitativamente, algunos datos serían: el número de células neuronales, 10 mil millones, es equivalente a las estrellas de la vía láctea, las neuronas se comunican entre sí por un notable fenómeno llamado "sinapsis", cuyas conexiones se cuentan por billones.

El cerebro es producto de la evolución de las especies, cuya parte más antigua, el tronco cerebral, la compartimos con la edad de los reptiles.

El sistema límbico, centro de las emociones, es propio de los mamíferos, con una antigüedad entre 30 y 500 millones; y el neocortex, que es la parte más nueva, la humana, que ocupa el 75% de nuestra caja craneal, sólo tiene un millón de años. Llevamos, de hecho, decía Darwin, la evolución en nuestro cerebro.

Cualitativamente qué decir. Aquí sólo podemos apuntar que lo más notables e insoslayable es, en efecto, la unidad indisoluble de todas las estructuras cerebrales, las complejísima e inconmensurable red que constituyen las neuronas y sus sinapsis, las cuales mantienen en prodigiosa interrelación las múltiples regiones y funciones cerebrales.

Esto significa, en términos latos y extremadamente genéricos y vagos —que son los que podemos utilizar aquí—, instintos, emociones y razones, fuerzas inconscientes y aspiraciones de la consciencia, impulsos de reptil, de mamífero y de humano; porciones y valoraciones, ley de sobrevivencia e imperativos éticos de la razón; naturaleza natural y naturaleza ética y espiritual; en suma, conforman una realidad integral, intrínsecamente indivisible, de tal forma que la naturaleza esencial o espiritual quedaría aparentemente, o, de hecho aquí, incorporada a la naturaleza biológica del hombre. Ésta concentra en sí misma las facultades del alma.

Como era previsible, los desenlaces monistas y reduccionistas han sido inmediatos y frecuentes en las interpretaciones de los hallazgos genómicos y neurobiológicos, particularmente la naturaleza libre y ética del ser humano queda como oscurecida, y llega incluso a concebirse como una especie de mera ilusión, o alguien dirá que todo es mero folclor.

Se sostiene así, que no hay más que una naturaleza, y ésta es la natural y material, regida por leyes estrictamente deterministas. Se borró la línea del horizonte; dijo alguna vez Nietzsche: "se ha borrado la línea del horizonte, no hay arriba, no hay abajo, no hay adelante, no hay atrás, caemos, caemos".

No obstante, en su creciente desarrollo, las propias ciencias naturales apuntan hacia la superación de las interpretaciones reduccionistas. Comienza a entreabrirse así la posibilidad de que sin postular dos realidades separadas, se reconozca la irreductibilidad de las funciones espirituales, y con ello su autonomía y su propia identidad.

Se inicia lo que Pierre Changeux, llama "la conquista del espíritu", y entra en escena el emergentismo de Mario Bunge, el monismo anómalo de Davidson, la unidualidad de Edgar Morin, la consciencia no se reduce a meros eventos neurológicos, se trata de una realidad continua, discontinua al mismo tiempo, según dicen Changeux y Ricoeur.

Se produce, asimismo, un significativo renacer de Spinoza, para quien existe una sola sustancia en dos modos de ser conocidos: cuerpo

y alma, y también se llega a dar una renovación de la consciencia dialéctica por la cual puede reconocerse la compatibilidad de los contrarios, particularmente del determinismo y la libertad.

Son así señaladamente decisivos, por una parte, el reconocimiento de que el hombre genético neuronal es necesariamente sí mismo, tiene un *selft*, es el agente de su propia existencia; y, por otra parte, también se reconoce que el humano es, como diría Heidegger, ser en el mundo y ser con nosotros.

Los genes se encienden y se apagan en función de eso tan simple que se llama "la experiencia vital". El cerebro, en su plasticidad, es afectado por la realidad, la cual a su vez es modelada, alterada, convertida en mundo por la acción humana cerebral.

Con el lenguaje incrustado en el área de Broca, se tiene incrustada la existencia del otro, del tú, del ser con, y con ello nuestra esencia simbólica comunitaria, y tenemos también incrustada ahí esa esencia, en las llamadas neuronas espejo.

Cerebro-mundo, yo-otros, natura-cultura, constituyen una interrelación de tal radicalidad, que, en efecto, no se comprende lo uno sin lo otro; al mismo tiempo que cada dimensión es irreductible a la otra, y mantienen una paradójica independencia sin ruptura: unidad-dualidad simultánea.

Ciertamente, no hay espíritu sin materia, pero el espíritu como tal no se reduce a materia. Por extraordinariamente prodigiosa que la materia sea en cuanto a tal, no hay historia sin materia, pero la historia no es material, ni materia.

Por otra parte, destaca también que el propio conocimiento neurocientífico llega a poner de manifiesto que la neuroplasticidad del cerebro es signo de su carácter inconcluso, inacabado, susceptible de autotransformación en su existencia biográfica y en su existencia histórico-cultural; susceptible, en suma, de realizar las potencialidades más distintivas de la condición humana, entre las que está la eticidad.

El cerebro está, en rigor, genéticamente programado para la libertad, como dice Mosterín. Todos estos nuevos conocimientos de la naturaleza bioética del hombre nos llevan a la recuperación de su *areté*, de su excelencia y de su genuina virtud; nos llevan a reencontrar la línea del horizonte, trazada ahora dentro de la propia interioridad humana, desde la propia complejidad de su cerebro.

Es verdad que tal naturaleza bioética abarca ese todo cerebral, impulsado por las fuerzas más arcaicas y poderosas de la animalidad que nos constituye, en conjunción con los poderes muchas veces ambivalentes de la inteligencia.

Bien y mal reinan en el centro de nuestra condición bioética, y reina con ellas también el conflicto, pero —sigo aquí una vez más a Ricoeur y Changeux—, de las potencialidades fundamentales dentro de nuestra condición natural, hay un impulso hacia la maldad radical, aunque más radical y más originario está el impulso hacia la bondad; o sea, aquello que Spinoza dijo: "todo lo que es, tiende a perseverar en su ser".

Me parece que esto es simplemente un mero esbozo que estoy tratando de comunicar, que nos abre otras formas de pensar nuestra condición ética, y de ahí, de esta condición ética ver cómo están fundados los principios, las normas y las verdaderas posibilidades de una realización bioética en el ámbito, no solamente teórico, sino en el ámbito de la práctica y de la aplicación. ◗

3.5 Session 4

Chair: Alex Capron
José Ramón Cossío: *Propuestas para la regulación del tratamiento de las muestras biológicas y los datos genéticos humanos*
Maria do Céu Patrão Neves: *The New European Regulation on Clinical Trials*
Ruth Faden: *HeLa Cells, Social Justice and the Ethics of Science*

a. Introduction

Cossío reminds us that legal frameworks and justice play an integral role in engaging with ongoing bioethical dilemmas, and the courts and

legislatures must be engaged with current issues and debates. Ethics committees alone cannot always anticipate issues that may arise in the future, though they must resolve cases and make decisions in the present. Prominent examples include questions regarding the use of samples obtained under informed consent, but which with the development of new technologies may become able to be used in new ways, reveal new and useful scientific knowledge, but which may not have been contemplated under the original consent.

The moral status of DNA, for example, which can be extracted from samples given under consent, may very well be ambiguous. The law, however, is an instrument that is meant to resolve ambiguity. The methods and matters by which legal analysis and resolution proceed help to ensure that there is rational input by interested stakeholders, for instance those holding samples and those representing populations and individuals who may have contributed those samples. Through reasoned, legal analysis, by lawmaking and interpretation, and by judgments administered not only by ethics committees but also, where need be, through courts, greater predictability and hopefully justice will better prevail.

Professor Patrão Neves discusses the law in another context, that of international treaty and agreements. Namely, in the context of European regulations concerning human trials and informed consent, an important aspect of modern clinical study is raised and discussed. How do we manage the conduct of international medical, clinical trials in a multinational context, where in the past State sovereignty has helped develop differing norms, rules, regulations, and legal frameworks for the conduct of human studies? Can we and should we seek harmonization among differing jurisdictions, and how will that be reflected in ethic committee composition, education, and processes?

One manner by which harmonization can be pursued is through international agreements. In the European context, there are bodies, like the European Parliament and the European Commission, which can serve as the context for such agreements. Science ordinarily proceeds ungoverned, and multinational research programs move forward without much in the way of regulatory friction because most of the institutions of science are organic. But protection of human subjects raises concerns outside of the ordinary course of science, and scientific processes cannot accommodate these concerns without some

outside influence. Unchecked, local norms and rules can significantly hamper science where human subjects are concerned and harms may result, even if only by delaying discovery. Thus, simplification of ethics approval procedures through single entry points, harmonization of ethical committee processes and benchmarks, and other manners of international regulation that would lubricate scientific processes involving human subjects rather than slow down and complicate international efforts, would seem to be worthy goals.

On the other hand, regulations and laws add layers of bureaucracy to science, and complicate both medicine and clinical science's conduct significantly. Investing in laudable goals like harmonization of clinical and human subjects ethics across borders carries with it the necessity of significant monetary investment, and the investment of additional time and personnel. Moreover, one area of concern in the admixture of law with ethics is reflected in the processes of informed consent, whose documents seem to grow in size making the probability of fully informed consent from all subjects lower. Lawyers often view the problem of informed consent as a matter of listing every possible risk, perhaps because of concerns about eventual liability. However, achieving informed consent becomes more doubtful the more verbiage is added to documents, and when a multicultural and multilingual cohort if involved, the complications abound as more words are used. It may well be that in order to conduct science ethically; the geographical scope of studies needs to be carefully contained, for now.

A final example of how ethics and even law can leave justice behind and require of us new solutions is that of Henrietta Lacks. Lacks tissues provided scientists with material for thousands of scientific papers, and stood as the basis for numerous scientific and technological advances in medicine. Her tissues were used without any of the sort of consent we take for granted as necessary now. An immortal cell line of cancerous cells taken from her, named by scientists the HeLa cells, which have been reproduced, spread, and studied for decades were the subject recently of attempts to repair the ethical circumstances of their taking and use. Should some recompense have been given for her contribution to science through the use of her cells, despite the fact that at the time there was not ethical context directing their extraction or use? What, if anything, might her family claim from the HeLa cells? Recent negotiations resulted

in a settlement of sorts, despite the fact that there was neither a moral nor legal foundation for negotiating or achieving a settlement. Nonetheless, a public awareness and moral concern led to a form of resolution.

Law, treaties, and other public pressures may all serve as institutional contexts for discussing and solving moral dilemmas in clinical research. Ethical theories often form the basis for the beginning of dialogue, but formal institutions play important roles in providing structure to ongoing debates and new or emerging problems in the ever-evolving world of bioethics. These writers offer us insights into each of these.

b. José Ramón Cossío

Propuestas para la regulación del tratamiento de las muestras biológicas y los datos genéticos humanos

Había preparado una presentación sobre algunas maneras de relación entre el derecho y la bioética. Sin embargo, lo que voy a presentarles es un modelo de regulación de información genética, que estamos trabajando en el Instituto Nacional de Medicina Genómica de México.

Tengo el gusto de ser miembro del patronato del Instituto Nacional de Medicina Genómica (INMEGEN), que dirige el doctor Javier Soberón. Cuando nos invitaron a participar en este patronato y tratar de ordenar algunos elementos del mismo, nos pareció que era muy importante generar un marco regulatorio lo suficientemente sólido para que el Instituto pudiera realizar sus actividades.

Este proyecto tiene mucho qué ver con los temas de esta reunión; desde luego, hay una gran cantidad de problemas relacionados con el ámbito ético en las actividades que realiza y que está por iniciar en un mayor desarrollo el INMEGEN.

Yo respeto y he aprendido mucho de los trabajos que realizan las personas que trabajan en el campo de la bioética, pero como abogado pienso que muchas de estas reflexiones, muchos de los problemas que se identifican o generan a partir de esta disciplina, tienen que tener una adecuada y una sólida traducción jurídica; si no la tienen, si no están bien articuladas las normas, todos los procesos regulatorios, los órganos que participan, lo que podemos tener al final son muy

interesantes reflexiones bioéticas, pero una poca eficiencia en términos jurídicos y en términos de socialización de estas mismas decisiones.

Lo que queremos hacer con este proyecto es generar un marco normativo, y sus previsiones generales, para en un diálogo con las autoridades de salud de México, tratar de identificar qué podemos hacer para resolver estas cuestiones.

El objetivo general es hacer un conjunto de propuestas de carácter jurídico para que el tratamiento de las muestras biológicas y la protección de los datos genéticos humanos, que se van a obtener y que se están obteniendo en el país, tengan una adecuada regulación.

La manera en la que estamos abordando el problema es a partir de cuatro puntos:

1. Queremos detectar problemas específicos respecto del tratamiento de la información genética y las muestras biológicas en el país.
2. Identificar las lagunas del derecho y las condiciones normativas que pudiéramos encontrar.
3. Emitir recomendaciones; desde luego, este trabajo no es de carácter legislativo o administrativo; simplemente buscaremos hacer recomendaciones regulatorias.
4. Garantizar o mantener un pleno respeto a los derechos humanos.

La manera en la que queremos atacar el problema está en esta gráfica.

Nosotros identificamos que hay cuatro grandes fines en relación con la información genética: el relacionado con la salud pública, la atención médica, la investigación para la salud, normativos específicos (tienen que ver con ciencia forense, procesos penales, normas administrativas, filiación, estadísticas, de acuerdo con el Instituto Nacional de Estadística y Geografía de México, y también los que tiene que ver con la identificación biométrica), y lo relacionado con la parte comercial. En un sentido de matriz, lo que tenemos relacionado con la obtención de la información, el análisis y su resultado, la comunicación y el almacenamiento de esta información.

Queremos relacionar cada una de estas actividades con los fines que tienen o que puede tener la información genética. Igualmente hemos encontrado que hay distintos elementos comunes a cada una de las cuatro actividades y fines que hemos participado.

En primer lugar, hay un sujeto-fuente, la persona a la cual se le toma la muestra; segundo, hay una condición particular del sujeto-fuente en cuanto a su participación en la obtención de las muestras; hay sujetos involucrados que, desde luego, no son el sujeto-fuente, personas que toman las muestras que llevan a cabo algunas operaciones; sujetos que son responsables del manejo de la información; sujetos titulares de esa información, que pueden o no coincidir con estos sujetos, y una característica de titularidad de la información.

Como metodología, lo que tratamos de hacer es conjuntar los elementos anteriores. Aquí tenemos la finalidad, que es la atención médica y la salud pública; un sujeto-fuente, que, desde luego, puede estar sano o estar enfermo, ser un embrión o un feto, un menor de edad, un adulto capaz, un adulto que esté en condición de incapacidad, un miembro de un grupo vulnerable o inclusive un cadáver para obtener información, sobre todo de carácter forense.

¿Cómo este sujeto fuente participa en este fin, firmando un documento, asintiéndolo o teniendo una disposición obligatoria, que permite recoger las muestras con o sin su consentimiento?

De los sujetos involucrados a los que me refería tenemos: a la persona que recaba el consentimiento, el que toma la muestra, el que la transporta, quien la procesa y las personas administrativas que la registran.

De los sujetos responsables tenemos: un equipo médico, un equipo de investigación, una institución, unos sujetos administrativos y las personas que, en su caso, tendrían que hacer una notificación epidemiológica en caso que se diera.

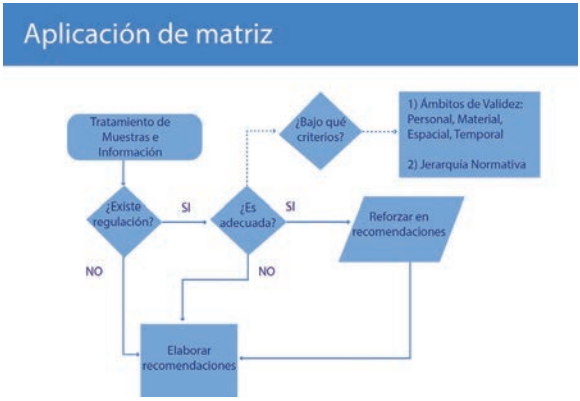
Además, tenemos a los sujetos titulares de la información, el sujeto-fuente, el disponente secundario, un investigador que esté trabajando sobre esas muestras, una institución y una autoridad sanitaria, y la naturaleza y la titularidad; se tiene un control, una propiedad, un beneficio, está en una condición de bien público o hay que destruir.

Lo que queremos es que cada uno de estos fines lo vayamos relacionando con cada uno de los sujetos y así transversalmente.

Los sujetos que aparecen en investigación o los participantes, los involucrados o los responsables no son los mismos que van a aparecer como sujetos que están en una condición normativa específica. Hay una variación.

Entonces, lo que estamos tratando de hacer es, a partir de una matriz, construir todas estas posibilidades para el efecto de identificar cada uno de los sujetos con respecto de cada uno de los fines en relación con cada una de las conductas que se pueden desplegar, y tener una matriz compleja, no una de dos planos, sino geométrica, de cada uno de estos elementos en la identificación.

Tenemos el tratamiento de las muestras y de la información. Hay muestra e información, como dos actividades. Lo que queremos hacer,



una vez que hemos identificado cada uno de estos cuadros, es saber, en primer lugar, si sobre ese tratamiento de la muestra o sobre ese tratamiento de información existe una regulación jurídica.

Si existe regulación jurídica, preguntarnos si es adecuada o no: si está bien identificado el sujeto, está bien identificada la materia, está bien determinado en el ámbito de las relaciones del sistema federal mexicano y está bien establecido en su condición temporal o normativa; entonces diríamos que esa regulación sí es adecuada respecto de ese cuadro específico, y consecuentemente lo único que presentaríamos es una recomendación en el sentido de que se mantenga.

Sin embargo, si no existe la regulación, haríamos una recomendación en el sentido de que es necesario regular determinado cuadro de esa actividad específica. Si existe la regulación, pero no es adecuada, también presentaríamos la recomendación de elaboración de esta actividad específica respecto a la muestra o a la información, bien sea que se trate para fin de investigación, comercial o lo que llamamos "jurídico," respecto de cada uno de estos sujetos.

Si vemos esto en su conjunto, lo que estamos tratando de hacer es generar un mapa para viajar, por decirlo así, normativamente; observar la mayor cantidad de particularidades, de regulación jurídica para ciertos efectos, y, como ya se dijo, donde hay una buena regulación, simplemente dejarla; donde no haya una buena regulación jurídica, proponer a las autoridades sanitarias del país la posibilidad de que generen por vía de leyes y reglamentos, de normas oficiales mexicanas o de lineamientos, las soluciones que permitan el manejo de la muestra y el manejo de la información que se está generando a partir del análisis de esa misma muestra.

Como miembros del patronato creemos —yo en lo personal y otras personas del equipo espléndido que tenemos— que con esto le podemos generar al país un buen marco regulatorio, un marco más fino, mucho más puntual, para saber de qué manera se pueden realizar estas investigaciones.

Haciéndolo mediante un proceso simplificado, estaríamos llevando a cabo un análisis jurídico para generar este diagnóstico, las propuestas de cambios normativos y la retroalimentación. Se trataría de correr transversalmente la totalidad del orden jurídico mexicano, leyes,

reglamentos, lineamientos, etcétera, para efectos de estas mismas cuestiones.

Desde luego, esto es aplicable en el abordaje; no se refiere a generar regulación. Eso le toca a la autoridad pública, pero le da sentido sobre quiénes pueden participar, quiénes pueden obtenerlo, cuánto pueden guardarlo, para quién pueden disponer de la información, esto en relación con los sectores públicos o privados en el país.

Quiero expresar mi reconocimiento para el equipo. A mí me tocó coordinar el grupo, pero el trabajo importante es de la doctora Alessandra Carnevale, del INMEGEN; el doctor Cristian López Silva, experto en cuestiones regulatorias; la doctora Davara, experta en el tema de privacidad de datos; Lourdes Mota, quien está vinculada con asuntos de regulación sanitaria; la doctora María Marbán, que estuvo muchos años en el Instituto de Acceso a Información; el maestro Rodrigo Montes de Oca, que también es experto en cuestiones de salud; Ana Cecilia Moctezuma, que trabajó hace algunos años en el INMEGEN, y la maestra Garbiñe Saruwatari, del INMEGEN, quien lleva a cabo todas estas actividades regulatorias. Como grupo, agradecemos la invitación del doctor Manuel H Ruiz de Chávez.

Creemos que este modelo se puede reproducir en otros estados, tratando, bajo esta matriz general, de identificar problemas, sujetos y procesos, para tratar de generar para México un marco regulatorio, desde luego no excesivo ni intromisivo, pero tampoco de una permisibilidad tal que cada quien pueda hacer lo que quiera con las muestras y con los análisis que se hagan.

Para mí es muy interesante esta relación entre bioética y derecho. En muchas ocasiones, la bioética nos ilumina los problemas para quienes estamos en el mundo del derecho, a quienes nos corresponde llevar a cabo regulaciones, pero también cuando nosotros en el mundo del derecho generamos las normas jurídicas para regular o para tratar de resolver algunos de los problemas que genera la bioética; hay una necesidad de comunicación porque, a veces, las mismas soluciones jurídicas son generadoras de problemas para la bioética.

Hay ahí un continuo entre problemas, soluciones y nuevos problemas, por lo que consideré interesante compartir con ustedes este trabajo que estamos llevando a cabo.

c. Maria do Céu Patrão Neves

The New European Regulation on Clinical Trials

My topic is the New European Regulation on Clinical Trials. I think this regulation is not only interesting for the twenty-eight member states that compose the European Union, but I truly believe that it is interesting for all of you, for the entire world, for two main reasons. First of all, it confirms a new model of policy for clinical trials. Secondly, it goes in totally different direction of the one that has been pursued for the majority of the countries. I was totally forgetting that I have here in my head.

I will start by going through very briefly the first European initiatives, mainly to point out that it is a coherent path that goes from the very beginning until today. Then, I will go to consider the proposal of the regulation. This is very important to understand: the proposal comes from the European Commission, and this proposal was made in 2012. This proposal was very controversial, especially in what concerns the ethical issues. Later, we have the regulation on clinical trials that was approved last April, so it is brand new; the regulation also addresses, of course, two main ethical issues the ethics committees in the informed consent.

Why? Because you could ask me, don't you go straight to the regulation and you start by talking about the proposal? The proposal was two years ago —yes, that's true—, but the proposal, which was very controversial —in my view— does reflect the real perspective, the real intention of the European Commission in what concerns clinical trials.

I don't think that it was surpassed, it remains, and it is persistent and if we have any doubts about that, by considering the whole path, since the very beginning until today, we will see there is a coherent project here. It really deserves attention the proposal of the Commission.

The first European initiative, there was one directive in 1965, a second one in 1975, these two directives were not really dedicated to clinical trials, but they did create a framework for clinical trials in Europe. Then, the directive of 2001, which is still enforced, was really

dedicated to clinical trials and it presented a very extensive and detailed ethical requirements.

We can say, in a very general way, that these three directives did draw a path, a very coherent one that became clear each step of the way. It's just like a project that unfolds. There are major orientations in these three directives. The first one is harmonization. If you read the directive of 2001, recital one, you see that the harmonization is quite clear there. Approximation of the laws of the member States are also there, uniform rules on the compilation of those years including their presentation. Harmonization is the word of order.

There is another main direction in these directives: centralization. Centralization, we read in a single opinion for each member State. You see, if we talk about centralization in Europe, this goes in a totally different direction of what we see in the other countries, because we are talking about one Institutional Review Board (IRB) in each country. We are talking about one single position, approval or refusal in each country.

What we saw in Europe until 2001, what we see now in the rest of the world is several IRBs, one IRB in each healthcare facility.

Ethically speaking, I would say that these first European initiatives do have very strong ethical concerns, specially the directive. I will point out some of them here: reinforce quality in safety, the ethical principles, protection of rights with risk assessment, better protection for persons who are incapable of giving legal consents. It's also in the directive of 2001 that ethics committees are established in a compulsory way for an approval of clinical trial, but, again, one for each member State.

Very important it is also to introduce the obligation of insurance. These are the three directives, the one that is still enforced, and now we move on to the proposal of a regulation.

The 3 UE Directives deepen the ethical concerns (and Directive 2001/20/CE):

- *Strengthen the protection of rights, safety and well-being of trial subjects* (risks assessment; data protection; persons who are incapable of giving legal consent to clinical trials receive special protection);

- *Establish ethics committees that, notwithstanding their number, will produce a single opinion for Member States* (in order to achieve an uniform position and increase the speed of the process);
- Introduce the obligation of insurance or indemnity to cover the liability of the investigator and sponsor.

Just a change of directive towards regulation, we see immediately that the harmonization is becoming stronger, because a directive can be changed in each member state; a regulation imposed itself as it is, so there is no change whatsoever.

In what concerns the proposal, the one that was made by the European Commission in 2012, we see that the harmonization becomes stronger. We have here again a single administrative decision by the member State concerned, but we have one single position for all European Union.

We asked for harmonization and also for simplification. Simplification, for instance, single entry, one application dossier, single submission, single safety reports, for twenty-eight member states. We can go a little further and see that besides harmonization and simplification we have also facilitation. Facilitation of procedures and I draw your attention, for instance, for the possibility of not reporting adverse events.

If the protocol provides already this possibility, reduced timelines for authorization and possibility of tacit authorization of clinical trials, so everything becomes quite easy. Again, centralization; but here we have a little something: not only centralization of procedures that were already placed in the directives, but we have —and this is very important— we have decentralization in what concerns ethical review and insurance, two major topics of ethical concerns. They are not centralized anymore, they become decentralized, and the proposal does not even refer to them as compulsory.

Ethical procedures are said —by the proponents of these regulations— to be linked and impossible to harmonize; therefore, either they fall out of the proposal; yes, they did, or they become a responsible for the member States as they now are in the new regulation. It's very difficult to understand this kind of arguments

because, of course, it is possible to have some kind of harmonization in ethical issues, Europe has the charter of fundamental rights; we have many international and legal documents, we have standards for minimal ethics, so harmonization is possible.

Even if it wasn't, we would ask —insurance is not possible either to harmonize? That is a very interesting question. If it not possible to harmonize, if it becomes a responsibility for the State member, then I would ask, we can have two European citizens that are under the very same clinical trial, that can suffer the same injuries, but if they are in two different member states, they receive different compensation. This is something that we have to look in more detail.

Of course, that this picture can be easily understood if we read the exposition introduction of the proposal. Where it is that? The number of the applications for clinical trials in Europe, between 2007 and 2011, fell 25%. Yet, costs for conducting clinical trials have increased; staff has doubled, increase of administrative costs, insurance has increased 800%, and the average of the clinical trial has increased 90%.

This is not the only thing that we read in the introduction of the proposal. We also read which the objectives are, they ensure attractiveness of the EU for contracting clinical trials, and establishing and functioning the internal market regards clinical trials and medicinal products for human use. That is, clinical trials are seen now as an economic sector and the engine of economic development.

No one really wants the sponsors prefer to outsource their clinical trials towards countries having less strict laws. The European Union really wants to make the European Union as attractive as possible. While the majority of the world's countries are reducing the number of clinical trials, the EU wants to increase their number. While the majority of the world's countries are committed to more strict rules, the EU wants to soften the clinical trial rules and to become more attractive.

Well, from the ethical point of view, the proposal presents two major problems. Ethics committees are no longer considered; informed consent is not very well developed, and it presents a brand new possibility of skipping informed consent in emergency situations. This was the proposal. The proposal was revealed by the European Parliament, by the European Council, and now we go very fast to my third and last point that is the regulation.

Indeed, in this regulation it was possible to make some important revisions, because it constituted that the European Commission's proposal neglected a significant part of the most relevant bioethical reflection of the last years, namely, in what concerns ethics committees and the strong requirements for informed consent.

The European Regulation proposal raises serious ethical concerns:

- *Ethics Committees*, which are no longer considered compulsory neither their advice needed prior to authorization (ethical aspects relate, in particular, to the need to obtain informed consent from the subject or the legal representative);
- *Informed consent*, especially the brand new possibility of skipping informed consent in emergency situations.

Now I will show you what is in the regulation that was approved last April, and that will come enforced in 2016, but it was totally absent from the proposal. I think that it speaks by itself: definition of an ethics committee was totally absent.

The European Commission's proposal neglected a significant part of the most relevant bioethical reflection of the last past years.

On the other hand, the Trilogue Agreement succeeded to introduce the right measures that follow from the wide ethical consensus on the present issue, namely in what concerns:

- Need for ethics committees; and
- Strong requirements for Informed Consent.

Here, member States are the only responsible to organize the enforcement of the ethics committees, it is now in the regulation and at least gives member states this possibility. Research projects should be reviewed; it was not, it is now. Ethical review from ethics committees prior requirement; it was not, it is now. Ethics committees advise binding. We cannot forget that this was deleted in the proposal. It is now, fortunately, in the regulation. Ethical and scientific quality; this is what concerns ethical committees.

In what concerns ethics committees

- *Definition of an ethics committee* (Article 2, 11);
- *Member States are the only responsible to organise the involvement of the ethics committees* (Recital18);
- *Research projects should be reviewed from the ethical point of view before being conducted* (R29);
- *Ethical review, from ethics committees, becomes a prior requirement for a clinical trial authorization* (A4);
- *Ethics committee advice is binding* (A8, 4; A14, 10; A19, 2c; A20, 7; A23, 4);
- *There are ethical and scientific quality requirements for good clinical practice* (A2, 30).

Let's move on to informed consent. I believe that the new regulation now in what concerns informed consent has tripled the size of the articles of informed consent. Now the regulation presents a very good overall statement about informed consent. The more complete that I know, but it was not so. Everything that I am about to show you now it was totally absent from the proposal: information in a prior interview in a clear language, opportunity to ask questions, time to consider the decision, consideration of specific situations, among others.

These specific situations that can affect free decision-making, economically and socially disadvantaged groups; all these details are now considered, with additional requirements in case of minors, incapacitated subjects, minimal burden, knowing your influence including that of financial nature, and there is more to come, special attention paid to the information needs of individual subjects, confirmation that information was understood and this is very rare to see and I am glad that it is now in the regulation; detailed specification of daily information, involvement of a minor capable of assenting; of course, clinical trials on incapacitated subjects and minors; enlargement of the vulnerable populations, explicitly considered such as pregnant and breast-feeding women and others, and here, on the other slide, we talk about military, prisoners and also, well, additional safeguards for clinical trials in emergency situations. This is something that for me is still open as a major problem.

Sometimes, people tell me: "well, if we really need from the medical point of view to have the possibility of engaging clinical trials in

emergency situations, and in this case, we do not have time, there is no possibility to ask for informed consent."

I proposed at the European Parliament that the same system that we have now in organ donation with the possibility of opting out would be also applicable in these cases. That is, we would have national registration for people that would not want to engage in a clinical trial in an emergency situation. This was totally neglected. It means that for every European citizen that goes in an emergency situation, he can become a subject of a clinical trial under specific situations and the specific requirements, it is true, that are much tougher now than they were in the proposal of the Commission.

In conclusion, the proposal of the European Commission was duly reviewed, but remains a very important indicator for the future steps in what concerns clinical trials. The EU regulation will have strong implications, I believe, in the rest of the world, because it will become enforced in 2016 for twenty-eight member States. It's impossible not to have an impact in the rest of the world. I believe that it can strengthen a similar orientation already existing in the USA. There are lots of papers about how different IRBs in the states issue different opinions about the very same clinical trial. That puts a question that, of course, the new European regulation answers.

I believe that reducing the number of the cities that clinical trials in South America, in Africa, because for Europe now clinical trials are a question of economic development.

Europeans want to have more and more clinical trials in Europe, so it is a question for them of competing with the other parts of the world. I believe if it succeeds the number of clinical trials can decrease in other parts of the world. Some current discussions, very hot discussions in what concerns placebo, or double standards, will lose somehow their importance if this regulation has the implication that I foresee.

Of course, it is also a question of proliferation of IRBs in these regions. Since now, in the European Union we have just one single decision for the entire twenty-eight member states.

My very last word. Well, that is the very last. Let me got to the other one. I believe that it does inaugurate a new paradigm in the clinical trials' history. First, it was science, the major value before the Second World War. After the Second World War, ethics was the most important

perspective for clinical trials and now it seems that market will be the most important one.

d. Ruth Faden

HeLa Cells, Social Justice and the Ethics of Science

Many of you, no doubt, are familiar with the HeLa story, perhaps through reading Rebecca Skloot's bestseller *The Immortal Life of Henrietta Lacks*.

I should have put the Spanish cover on this book. The book has been translated to fourteen languages, of course, Spanish, but thirteen others. Perhaps you also know about the HeLa controversy because of something more recent, which was the controversy surrounding the whole genome sequencing of HeLa. What has happened and is continuing to happen to the Lacks family has helped reignite global debates in the ethics of bio-sample science and genomics about consent and compensation, disclosure and privacy.

As important as these issues are, today I want to argue that they are impossible to resolve, independent of considerations of social justice. My comments are in two parts. I will begin by briefly summarizing what happened to Mrs. Lacks, her children and her cells, followed by an even briefer review of the ethics and science questions that are embedded in their story. In the second part of my talk, I hope I can show you that these questions are not independent of these wider considerations of social justice.

I need to start with the disclaimer. As Alex has already mentioned, I am on the faculty of Johns Hopkins, which is the institution where so much of the science part of the story took place. Also, I was one of two Hopkins leaders who met recently with the Lacks family and the top leadership of our National Institutes of Health about the genome sequencing of the HeLa cell line, meetings that led to a historic agreement between the Lacks family and the National Institutes of Health and the formation of the HeLa genome data access working groups—it is a long title—, on which members of the family and I sit. That is the disclaimer you will want to know.

Let's begin with part one, which is the story. Here you see a photograph of Mrs. Lacks; it is a kind of an iconic photograph of her that is seen everywhere. You can also see her husband, David Lacks, holding the photograph. These photographs were from an earlier one of Mrs. Lacks. I show them with the permission of the family.

In 1950, Henrietta Lacks was a poor African-American woman who had recently moved with her family to Baltimore from the South —in what is being called the Second Great Black Urban Migration from the rural South to cities to seek jobs after Second World War.

At the time, Mrs. Lacks was a young mother of five with little formal education. She was becoming progressively more ill with pain in her lower abdomen and eventually she went to Johns Hopkins Hospital for treatment. It is very important to know that in 1951, in the early 1950's, Hopkins was the only hospital in the region providing medical care to African-Americans. Unusual among American hospitals, it had been founded in 1876 by a bequest from Johns Hopkins, a local philanthropist who in his will specified, and here I quote: "that the hospital would provide care to the indigent sick of this city and its environments without regard to sex, age or color." Despite this requirement in the will, which was honored, Baltimore was nevertheless a southern city. Medical care, while provided to all, was delivered in segregated facilities.

Mrs. Lacks was diagnosed with cervical cancer in January of 1951. This was precisely during the time that Doctor George Gey, a Hopkins' faculty member was on a quest to accomplish what had never been done previously: to grow a human cell line that would be immortal so that it could serve as a standardized research tool. Doctor Gey was asking for tissue samples from any patient in the hospital, particularly patients diagnosed with cancer. On February 8, during Mrs. Lacks' first radiation treatment, which was the standard of care for cervical cancer at that time, a sample of her tumor and the healthy cervical tissue was removed and made available to Doctor Gey and to another research

physician. By late February 1951, within weeks of Mrs. Lacks' first treatment, the cells isolated from the tissue sample were growing without end —Doctor Gey had achieved his goals of creating an immortal human cell line.

These cells, now universally known as HeLa cells, became an essential tool of biological research. Almost immediately, they played an important role in the development of the polio vaccine, one of the most important developments in the 20th century in public health. Over the years, they had contributed to many medical breakthroughs, including the HPV vaccine that protects against cervical cancer, the disease that took Mrs. Lack's life. All total over 74,000 international scientific publications have used or mentioned her cells, 74,000. In keeping with the practice of the time, Mrs. Lacks' consent for the removal of the tissue sample and for its use in research was never obtained.

In October of 1951, Mrs. Lacks died in Johns Hopkins Hospital, never knowing of the extraordinary breakthrough in Doctor Gey's lab in that same institution. Her husband and her children did not learn of the existence of HeLa cells, or that the cells were being bought, sold and used in research until twenty years later. For many years, the identity of the source of HeLa was unknown or misrepresented as Helen Lane rather than Henrietta Lacks. When Henrietta Lacks' identity was made public, initially in 1971, this was without her family's authorization. Indeed, they were never even notified about their wife's and mother's role in the science, let alone that her name was about to be released to the world.

It is also important to know that Doctor Gey and Johns Hopkins did not profit in a direct financial way from this discovery. Again, in keeping with the time, Doctor Gey literally gave HeLa cells away for free to scientists and laboratories all over the world. Now, Gey and Hopkins did profit in other ways, of course, most notably in terms of professional standing. HeLa cells did go on to make a great deal of money for some in the biomedical industry. Mrs. Lacks's family never received any financial compensation. Her children grew up in poverty. Much of the public conversation stimulated by the HeLa cells story has focused on how we ought to think of bio-samples and on the science this samples can enable. These are familiar issues to many of us, to many of you.

Should patient consent be required for research? Does it matter if the bio-samples are removed for clinical purposes, taken solely for research purposes? What kind of consent, specific and traditional consent or broader general consent? As genomics and big data science advance, what kind of assurances, if any, can be made about privacy and confidentiality? Is the consent of the source sufficient? What about the family members, in the case of genomics research? What about compensation if a blockbuster drug or research tool is developed?

Now, these are fascinating important questions about the ethics of science. However, they are questions that cannot be properly answered as long as we think of them as only, or even, primarily questions about the ethics of science. They are about science, but they are also about how science engages society more broadly, including centrally questions of social justice. This takes me to the second part of my talk.

I really hope some of you in the audience know who this woman is. This is Tina Turner, one of my idols. I have titled this part of the talk *What has social justice got to do with it*. Perhaps, the best way I can bring the social justice theme into this picture is through the voice of Mrs. Lacks' daughter, Deborah, as related by the author Rebecca Skloot, and here I am quoting: "but I always have thought strange if our mother's cells have done so much for medicine, how come her family can afford to see no doctors. Don't make no sense. People got rich off my mother without us even knowing about from taking her cells and now we don't get a dime. I used to get so mad about that to where it make me sick when I had to take pills. But I don't got it in me no more to fight. I just want to know who my mother was." I now want you to consider in the light of Deborah's statement two counterfactuals. The first is this. What if Mrs. Lacks' family had received financial compensation from the commercialization of her cells? Would their story still be morally troubling? Why?

The second counterfactual is this: what if the details of the story were exactly as Rebecca Skloot relates them, no consent and no compensation, but Mrs. Lacks had been an affluent white person whose family was socially prominent, would their story still be morally troubling? Why?

To answer these questions, I need first to explain to you a little bit about how I think about justice and therefore how our social

justice aims can help alter how we think about ethics and science. Here I am working with a particular theory of justice that my colleague Madison Powers and I first presented in 2006. We have been actively refining and expanding what has come to be called the Twin Aim theory ever since. Our theory is focused on two things: the realization of multiple dimensions of human wellbeing and the identification of the main impediments to that goal. Justice, in our view, thus has two distinctive and neutrally reinforcing aims, hence, the Twin Aims Theory.

The first aim, or the basic wellbeing aim, requires that social arrangements secure in so far as possible six core elements of human wellbeing characteristic of a decent human life. What are the core elements of a decent life? These are the things that every one of us wants and every one of us needs, no matter who we are: the first is personal security from actual physical and psychological harm, as well as the threat of such harm. The second element is cognition, having an understanding of, and engaging deliberatively, with the natural and social world. The third element is personal attachments, let's see when I'm getting them, there we go, to love and to care for those that we love, both family and friends. The fourth is health. The fifth element is the respect of others, to have the social and political standing that allows a person to be judged and treated as a moral equal, a person worthy of the same sort of treatment any other person merits. The sixth is self-determination, living a life that is not under the domination and control of others, or the tyranny of profound necessity where tan individual can shape the broad controversy of her life and have some significant say of its general course.

The second aim, or the structural fairness aim, requires social arrangements to combat serious forms of disadvantages that are unjust because they are unfair.

The first aim focuses on the injustice of failures to realize the core elements of wellbeing that are characteristic of a decent life. The second aim focuses on the injustice of creating and maintaining serious social impediments to experiencing adequate levels of wellbeing. Such impediments are generally multiple and mutually reinforcing, and they systematically favor some at the very great expense of others, included within the purview of the structural fairness aim are invidious and

discriminatory social status norms and practices, as well as the endorsement or toleration of oppressive religious and cultural practices.

Finally, there is the special case of childhood where the failure to secure in childhood sufficient levels of wellbeing frequently results in deprivation at this critical stage in human development, in ways that profoundly disadvantages a person over the course of a lifetime making later gains impossible.

I am now going to have to rush through the rest of my talk. I want to connect this with justice. I want to connect the story now back to justice so understood and let's return to the counterfactuals.

What if Mrs. Lacks' family had received financial compensation? Well, of course, with any luck, money would have made a significant difference in the wellbeing of Mrs. Lacks' family. The money would have come however well past the children's early childhoods. It would have done little to mitigate or narrow the more systematic egregious injustices that the Lacks children experienced by virtue of being poor and black in the United States in the second half of the 20th century. It is for this reason I submit to you these reasons that the HeLa cells story has become so powerful.

What is wrong about what happened to the Lacks family engages every core element of human wellbeing of our list: assaults on respect, on self-determination, on cognition, on attachment, on personal security and health. Mrs. Lacks and her children were poor black people in a segregated world in which the most profound injustices, racial oppression, were daily features of their lives. The children suffered regular hunger and regular abuse, when they were little, without any interference from the State, any kind of child protective services. Moreover, well into the 1970s, there were continued instances in which the Lacks family were not treated respectfully as moral equals, for example, when they were asked for and provided blood samples without understanding that their samples too were being used to advance science.

Now, let's consider the second counterfactual. What if Mrs. Lacks had been affluent and white and her family was socially prominent? Would their story still have raised moral concerns? Well, here the answer depends on whether we think a socially prominent white family would have been treated like the Lacks family was treated. Here I want to give you another quick quote from Babette Lacks, who

is Mrs. Lacks' daughter in law, her eldest son's wife. What really would upset Henrietta is the fact that Doctor Gey never told the family anything, "We didn't know anything about those cells and he didn't care. That just rubbed us the wrong way. I just kept asking everybody, 'Why didn´t they say anything to the family?' They knew how to contact us." The publication of Rebecca Skloot's book, and more recently the whole genome sequencing of HeLa, has generated an enormous discussion about research. How it should be conducted going forward; what kinds of consent from whom; compensation and so on. From the standpoint of the Twin Aim Theory of justice, however, there are other key questions that should be asked as we vet alternative public policies and necessarily inform how consent and compensation challenges should be addressed.

I'm going to take about one minute here. It is critical, for example, that we consider the impact of any policy that's being considered on existing unjust inequalities, not only unjust inequalities in material goods and resources, but also inequalities in social and political standing fuelled by existing patterns of systematic disadvantages. Whatever policies we adopt for consent for maintenance of samples, for disclosure will affect people differently depending on who they are. It is also important to think about the wider web of related social institutions in which any policy would necessarily be embedded and asked, is that wider web of related social institutions, in this case vocally the institutions that affect health and health care, just to all affected?

It is likely that Mrs. Lacks' family, and here I conclude, and Mrs. Lacks' friends, her community, did not benefit from some of the very scientific advances made possible by HeLa cells. It is a certainty that they did not experience the security of knowing in the event of illness that they would be able to access these advances for themselves and their loved ones. As with so many, there was no guarantee their lives would benefit from the science made possible by access to human tissues. For us, more than anything, the Lacks' family story must be about the inextricable relationship between the ethics of science policy, how it should govern bio-banks, genomic research, electronic health records and so on, and the ethics of health systems and the other social foundations of human well-being is about how the least of us live and about social justice. ◗

3.6 Session 5

Chair: Simón Kawa Karasik
Andrew Haines: *Climate Change and Human Health. Ethical Challenges*
José Sarukhán: *Elements of an Environmental Ethics*
Evandro Agazzi: *Bioethics as a New Paradigm of Ethics for the Contemporary World*

a. Introduction

One of the great virtues of the field of bioethics among scholarly pursuits, and as practiced in the world, is its ability to encompass so much. Besides the already broad realm of medical clinical and research ethics with which the field is typically associated, and from which it evolved, bioethicists now must grapple with issues regarding non-humans, biomes, and the biosphere. Perhaps someday we will also investigate exo-bioethics as our inquiry moves out into the solar system and beyond, perhaps even to discover life beyond Earth. Meanwhile considerable challenges are presented by such phenomena as climate change, and bioethicists must begin to consider whether and how ethical principles previously focused primarily upon human subjects might be expanded to issues of global climate change.

Within the past fifty years, bioethics has grown to consider duties we owe to animal subjects in experimentation, altering the manner by which we conduct such research, and encompassing some values that ought to direct our use of animals, even as the Nuremberg Code states, animal experimentation is required before human subjects may be employed. The way in which we treat non-human life is now quite different than it was decades ago, and our notions about future use of animals continues to evolve, with some suggesting that an overarching goal must be to avoid using any conscious life form as a means to an end. Considerations of the rights of animals aside, there are reasons to examine under the rubric of bioethics our duties to each other and ourselves as expressed through behaviors to biomes and the biosphere in general.

Professor Haines delves into the general problem of global climate change and its various implications. The climate is certainly changing, and there is an overwhelming scientific consensus at least about the nature of the change, both in its speed and direction. There is also considerable evidence about the cause of the change: the accumulation of so-called "greenhouse" gases, including CO_2, methane, N_2O and others associated with industrialization among other things. The planet's climate change is reflected in a number of phenomena, several of which are proving detrimental to human and animal life, and which, if continued, will fundamentally alter the relations of humans to their environment, as well as the abilities of numerous species to survive as they have. Significant adaptations will have to occur, especially for the tens of millions of humans who now live in coastal areas that may soon be under water. The costs in dollars will be tremendous, and adaptation is not ensured. The costs to health, not only for humans and non-human animals, but also of entire biomes will also be tremendous, and our food production will also require restructuring. The ethical implications are clearly many, and the solutions unclear, but they certainly fall within the broad ambit of bioethics, which is concerned with how we treat research subjects. In many ways, what we are doing to the climate is an ongoing experiment, unguided by ethical reflection, but with life on earth as the subject.

Humanity itself faces strains from its unrelenting growth. As much as humans are responsible for changing their planet's environment, so too are we responsible for the effects of our increased life spans on the population and demographics of the world. Professor Sarukhán considers, in light of our role in changing the climate through our industrial growth, further threats to human health and wellbeing as a result of population growth. Even as we ought to consider solutions to global climate change, from an ethical point of view, as belonging to the political sphere, so too must we consider that humanity must focus on sustainability in a broad sense. Limits to growth certainly exist simply by virtue of the scarcity of certain resources, and the nature of some of those resources as commons, which remain ungoverned and perhaps ungovernable by law or agreement. Might there be a moral basis by which we can craft a norm of sustainability, one that helps to guide our decisions and actions in a world of shrinking available

resources, growing populations, and climate change? Ethics should embrace these questions, and we must begin to grapple with an expanding field of moral considerations in our approach to the field if bioethics is to remain relevant at all to human affairs in the long run, if there is to be one.

Finally, Professor Agazzi brings us back to the question: What does bioethics mean? What is properly within its scope? As we have seen repeatedly, our contributors view it as a shifting, growing field whose boundaries are not clear. Perspective about the discipline can perhaps be gained by viewing ourselves as techno-social entities, quite different from the ideal agents described and assumed by ethical theories for millennia. We are, in a sense, artificial, not natural creatures emerging from innocence. We are creations of our environment, and creators of it. Everything with which we interact, from our tools, to our current lifespans, is a product of our creation. The ethics that emerges from a techno-social appreciation of humanity is markedly distinct from the ideal agents of philosophy. So too might our norms be seen as artifacts, entities of our creation, something we create rather than seek. The holistic ethics that modernity demands must be much different, and is reflected in the evolving nature of such fields as ours.

The method and matter of modern bioethics is, thus, seen as a move past the dualism of theoretical ethics, where ethical ideals are to be discovered and properly applied to decision-making and actions. Rather, we see in the action of bioethics, through conferences, publications, ethics committees, and the large amorphous mass of us considering ourselves to be bioethicists, the active creating of norms. Technological man creates norms just as surely as we create tools, and we adapt them to our ends, implementing them in our institutions even as they adapt and change according to our built environments.

These contributors show us the tremendous vista of bioethics yet to be generated, but which we are beginning to comprehend and discuss. They open our eyes to its potential, its importance, and to its evolving practical and theoretical aspects, all of which we should expect to lead the dialogue beyond these pages into the next century.

b. Andrew Haines

Climate Change and Human Health Ethical Challenges

I'm going to talk about the public health implications of climate change. What I want to do today is to make the case that climate change poses some very serious ethical issues. I hope that this will stimulate greater engagement by the bioethics community.

I don't think there's much doubt now that the climate is indeed warming. Most of the world has warmed very substantially since 1901 and, in parallel with that, the sea level has been rising —as waters become warmer, sea level rises and the Artic Sea ice has been declining. The evidence is now very strong: the climate is changing and human activities are the key factor.

The most important greenhouse gas is carbon dioxide, responsible for about 75% of global warming. It's important because it stays up in the atmosphere for a long time, so every molecule of CO_2 that we put into the atmosphere stays up on average about a hundred years; 20% will be there in a thousand years' time. We can't, at least with our current knowledge, easily bring those levels down, and levels have been going up dramatically. After 1970, CO_2 emissions have more than doubled, compared with the time before 1970. We see an accelerated level of CO_2 emissions, and other greenhouse gases like methane.

There are also profound changes taking place in the regional patterns of greenhouse gas emission, so they're shifting along with the changes in the world economy. The high-income countries and their levels of emission have almost peaked. Then we have the upper-mid income countries that are rising very rapidly. The lower-middle income countries are following them and the poorest countries are still not rising very much. Those people are not benefiting very much from fossil fuel powered development. This immediately shows you that there are profound inequities that are just beginning to be closed and indeed in the case of the poorest countries, they are not really narrowing. The profound inequities in the amount of emissions and in the benefits that have been resulted from those emissions, because our development pathways are dependent of course on the combustion of fossil fuels for our wealth and development.

What would this mean? That this could very easily lead to a 4° warming, and that's an average warming. Over land, that will be even greater. Can you imagine, for example, what Central America or what Africa would look like if it was 5° or 6° warmer? That could happen by the end of the century unless we do something very dramatic. It's going to be very difficult for us to bring climate under control; we would have to reduce emissions almost immediately. Of course, these changes won't just affect temperature; they would also affect rainfall patterns. Much of Mexico, parts of the US, northern parts of South America, parts of Africa and the Mediterranean and Australia, are all likely to suffer from reductions, so that means a probability of an increase in droughts —whereas in other parts of the world there could be increased floods.

At the moment, we have a limited window of trying to keep temperatures within 2° warming. That's a level beyond which, many climatologists think, we get into very dangerous possibilities of rapid climate change, rapid sea level rise and so on. We really only have about 255 billion tons of carbon left to emit, if we want to have a reasonable chance of keeping within 2°, and last year, we emitted about 10 billion tons. This means that carbon budget will essentially all be spent in about 25 years. We have a very limited time to reduce our emissions down to a level, which will keep us within 2°. We have to do that in a way in which equity were improved as far as possible.

This raises profound ethical questions. What is a just distribution of the burdens of mitigation? By mitigation I mean reducing emissions. It says in the UN Framework Climate Change Convention, that parties should protect the climate system on the base of equity, and with common but differentiated responsibilities, based on historical emissions, of course. What is a just distribution of rights to emit greenhouse gases? Should we move towards an equal per capita view, what's been called contraction and convergence? Should we acknowledge the fact that rich countries have benefitted already from greenhouse gas emissions for their own development and, therefore, they need to reduce it even more than that? These are difficult and controversial questions but they need to be addressed. We need to understand the ethical relevance of past emissions for the just distribution of burden rights.

Climate change can, of course, affect health in many ways, both directly and indirectly. Some effects of global warming are related to extreme weather events, some to vector-borne diseases, water- and food-borne diseases. Perhaps the most important is malnutrition and the amount that would depend on modulation, how much we develop —particularly in poor countries—, and how much we can adapt, either spontaneously or through planned adaptation.

What sort of deaths might be caused by climate change? We have some estimates of deaths. Obviously they are uncertain. The World Health Organization estimated that perhaps 150 thousand deaths occurred by the year 2000 as a result of climate change, many due to malnutrition, but also to other conditions. What's very striking of course is that if we had a simpler map of greenhouse gas emissions, it would be almost the converse of that, so the countries that are emitting most will at least in the near term have the lowest health impacts, but of course, in the longer term, the whole world will be affected.

There are many other effects of climate change. One of them is, of course, the inability to work: as the world gets hotter, it becomes more difficult to work, particularly outdoors. What we experience today is a monthly minimum labor capacity and you can see that for much of the world, there is a reduction to perhaps 60% or 70% as a result to thermal stress. But under climate change, with 3° of global warming, work capacity will be reduced to perhaps 10% or 20% of the labor capacity. That means ruin for many of subsistence farmers, it means many poor people would not be able to work outdoors, they won't have air-conditioned tractors, and they won't be living in air-conditioned houses. This is a profound ethical, public health and economic challenge.

We know that heat waves can cause excess deaths; the one in Europe in 2000 caused probably around 70,000 and we know that the probability of these heat waves will increase with climate change. The temperatures that seem very extreme in 2003 will become the norm. In fact, they would all be exceeded as the century goes on, unless we radically reduce greenhouse gas emissions.

2010 was an extraordinary year. Was it a warning or a harbinger of things to come? There were 20 million people affected by floods in Pakistan, about 12 million in China and of course, the Russians had

profound fires, over 50,000 people died in the heat wave around Moscow and the wheat harvest was affected so they stopped exporting and food prices went up in many parts of the world. It was a very big impact on health and development, and it's the kind of thing we might expect with climate change.

Many millions more are projected to be flooded as a result of sea-level rise by the end of the century. The Ganges, the Nile, the Mekong and so on, the Mississippi, are all areas where very large numbers of people could be threatened by sea level rise.

The effect of climate change on malnutrition is also very important. A whole range of different studies tend to suggest that crop productivity, availability of food, therefore, will be reduced in many low-income countries. Some increases might be only temporary, and if we look towards the end of the century, even in some of the high-income countries, we might start to see falls in crop production. This poses a very serious threat to food security, and we already have a billion people suffering from food insecurity.

What is dangerous anthropogenic, in other words, human-induced, interference with the climate system? This is important because this is what's in the UN Framework Climate Change Convention, which the world is negotiating on, and we have to come to an agreement by the end of 2015. I would submit that we already have good evidence that there is such dangerous interference and we need to minimize that.

What is a just response to risk and uncertainty? There will always be uncertainties. We can't be sure how many people will die in a hundred years' time, but as the UNFCCC points out, where there are threats of serious irreversible damage, lack of full scientific certainty should not be used as a reason for postponing such measures. Sadly, as we know, progress has been very slow. What are the physical behavioral and technological limits to how much we can adapt to climate change and who should pay for that adaptation? Clearly, the bonus should be on the countries that have benefited from the emissions of fossil fuels so far. There are a number of limits to how much we can actually adapt. Even in my own city, London, the Thames barrier will need to be replaced in the latter part of the century in order to deal with rising sea levels and, of course, small island states and some parts of coastal regions are already threatened.

The IPCC, the UN Intergovernmental Panel on Climate Change's recent report, in executive summary says, "The duties to pay for some climate change damages can be grounded on compensatory justice and distributive justice." At the same time, there are important benefits to moving towards a low emission economy, a low green gas emission, in several sectors: housing, transport, food, agriculture and electricity generation. There is a whole range of benefits for moving towards a low carbon economy, over and above the benefit of preventing climate change. One example, of course, is the reduction of air pollution and the WHO has recently estimated that about 3.7 million deaths a year are caused by ambient fine particles and 4.3 million deaths a year by household air pollution from solid fuels, particularly, among poor people. That adds about 7 million deaths a year totally —you can't just add the two together because there's some overlap between them— , and many of those could be reduced if we could reduce the burning of coal, for example, and also provide clean energy to low-income households, as well as reducing the combustion of fossil fuels, for example, diesel fuel.

This raises the important ethical question, should we prioritize mitigation policies, i.e. greenhouse gas reduction policies, on the basis of their healthcare benefits? I would argue that in some cases it does make sense because if we value these health care benefits they can help to offset some of the costs of moving towards a low carbon economy. What are the moral constraints on mitigation policies? For example, nuclear energy is controversial in many parts of the world because of catastrophic events that have happened before. How do we address the very real effects of climate change? There are many other pros and cons for other low carbon policies; regarding procedural justice, who has a right to be included in these decision making process around mitigation and adaptation? So far, those people who are the most likely to suffer, and are suffering from the effect of climate change, are effectively often excluded from direct consultation. What obligations do we, the current generation, have to future generations, both in terms of preventing dangerous climate change and distributing the cost of mitigation and adaptation? Shouldn't we, who have benefited so much from the current economy that we live in, be prepared to pay a little more in order to move towards a low carbon

economy? In the UNFCCC treaty it says that the party should protect the climate system for the benefit of present and future generations of human kind on the basis of equity.

Why aren't we moving forward? Well, this is a complicated question; there are many answers to it. There is a whole range of barriers to policy change, one is vested interest —the fossil fuel industries are very powerful. There is an organized denialism in some countries and there's a brilliant book that I would recommend to those of you who are interested called Merchants of Doubt by American historians Naomi Oreskes and Erick Conway. They show that there is a small group of people, supported by very powerful interests, who have —what they call— obscured the truth on issues from tobacco smoke to global warming over many decades. What they suggest is that it's the same kind of interests of the working class to obstruct movements against climate change. Many of our political leaders have very short-term perspectives. They are interested in the next election, not in future generations, or even twenty or thirty years down the line. Of course, we have a divided and often confused public. I think there's still a lack of awareness and knowledge about climate change. Perhaps people think that there are more doubts about climate change than there really are. There are some doubts, but the broad science is pretty clear.

Finally, there's a perception that change is very expensive and difficult. The IPCC, again, the UN intergovernmental panel, in its most recent report has shown that actually, if we can mobilize a whole range of technologies we have now, and technologies we could have in the future, the extra costs really would be very small and they have to be set against a rapidly growing world economy. Of course, if we carry on without reducing greenhouse gas emissions, that economic growth particularly towards the end of the century is really under threat. I believe that there are overwhelming reasons to move now.

In conclusion, what I would like to say is that climate change does have far-reaching and potentially catastrophic impacts on health despite the uncertainties. Many of these low-carbon policies in, for example, energy, in transport, food and agriculture, housing, can actually improve health and they can improve the economy as well. I think the challenge for our generation is to try to avoid that catastrophic

scenario, as this report from the World Bank says, "We've got to turn down the heat, we've got to avoid that 4° future," because that would be intensely damaging for our children and grandchildren's generation and future generations and we have it within our hand to actually dramatically reduce the chance of catastrophic events. I hope that I've convinced you in the ethics community that this is a serious ethical challenge, that we in the public health and the climate change communities need your support and your analysis to advance our knowledge, advance our theoretical analysis and understanding of this key topic for the future of humanity.

c. José Sarukhán

Elements of an Environmental Ethics

I am not a bioethicist; I'm not a philosopher. I'm a population ecologist who is working with global environmental issues and is really deeply concerned with what's going on. I will just jump into the matter of what I think ought to be done towards the environment, the planet in which we live.

Very quickly. There are three root factors that are generating the kind of problems that Doctor Haines addressed and I am going to mention very quickly. One of them is population growth, which is really going still at a very strong pace; it's still at an exponential phase. The second is the demand of resources and energy, which every one of us makes. Be clear that this is a problem: the individual demands that are generated by multiple causes all over the planet, in some cases really small, in other cases, absurdly high. Also, the third is the technologies that we are having or we are using in order to satisfy the needs that every individual in the planet has.

Those first two drivers, root factors, generate two main kinds of problems at the global level. First, it affects the ecosystem and environmental services that these ecosystems generate; the loss of all these —which is spoken as the loss of biodiversity, which is not the right way of addressing this issue— means the loss of the environmental

matrix that supports not only our species, but the rest of the species of the planet. Second, is global climate change, though obviously generated by the amount of resources and energy demands that every person has, this affects directly human wellbeing, and —as Doctor Haines mentioned— it affects in an extremely unequal way in the planet. There are a number of issues here that are important.

I am not going to give you a lecture on resources and human population and global environmental problems. Instead, I will argue that we are really affecting profoundly the planet we are living in, in all senses, and that all this brings about a series of problems. Just to go quickly on this issue of environmental ethics, which is not the most advanced area of bioethics worldwide, I will mention that there are two distinct but related extremes of thought in this area. One of them is the one that has to do with the relations with the environment itself, particularly with ecosystems, and the concern about other species that live in the planet which are deemed as vulnerable or sensitive, etcetera. Most of the discourse in this area has gone into the ethical responsibility that humans have on the preservation of these species. That's one approach. The other, which I think is also very important, concentrates on the relations among the numbers of our species, both present and in the future. There are two ways of addressing these problems.

The majority of those arguments focus, as I said, on the first relation, which is with the general environment or with specific species in the environment. I'll go into that in a moment. This approach on the first part of the relation towards environment is deemed eco-centric when the consensus are of an ecological type or biological, due to the intrinsic value of nature, or anthropocentric, because some of these approaches emphasize the importance of conserving the environment for the benefit of mankind. There's a big debate on which one is more legitimate and all that. I won't go into it because I really don't think these things address truly the problem as I think it should be.

There are some ethical dilemmas that need to be considered integrally, that come out of these kinds of approaches. The first is that we have a responsibility towards nature, but not only the species that are deemed as sensitive like species which have social structure, or

that have some obvious means of communication and things like that, but all nature, because all species have evolved, included ourselves, in an eco-systemic context. This is omitted completely from the discourse of the ethical relations of humankind towards nature. Ecosystems are completely out of the scenery in these discussions. The second thing is that we share genes with all the species with which we live in this planet in different degrees, almost close to 90% with the closest primate, down to 18%, 20% with plants. There is an original relation here that I don't think can be simply ignored.

The second point is that we have a responsibility towards all humans. Yes, we have a responsibility towards the environment, but we also have a human relation there that we have to take into account, both the present-age generations as well as the future generations. There is very little that has to do with what kind of actions we should take towards the incoming generations. We don't know. They are far away in time and this is a very, sort of, intangible concept that doesn't weigh very heavily in people's minds.

The other thing is that we are not considering ourselves as belonging to a biological species. It is accepted in appearance, everybody would say, "Yes, yes, certainly, I am homo sapiens," but it doesn't really convey what it means to be member of a species that evolved about a million years ago and has generated a cultural evolution that brings us where we are, and that we have a really strong responsibility towards those future generations. I think this so-called anthropocentric focusing towards environmental ethics is something that should not be done.

The third point is that these previous responsibilities, the one towards only the environment and the other that has to do with our species, are really embraced and considered by one concept, the concept of sustainable development, which really covers, on one hand, the integrity of the ecological systems, if we want to have a sustainable development, but also it is applied for the human benefit or wellbeing for present and future generations. This is something that again is spoken by everyone, everyone is doing sustainable development, even the mining companies in Mexico consider they are doing sustainable mining; that is an oxymoron, ambiguous as that one, I don't know of any other one. The thing is that this concept implies the need for

defining, both individually and socially, what level of satisfaction, of wellbeing, of comfort, that may sustain the environmental matrix in an indefinite way can be reached; one that will permit really access to everyone with equity, with justice for everyone —which is something we don't have. The amount of inequity, social inequity, the economical inequity in the planet now is really inacceptable.

Now, how do you define these levels of satisfaction? It's not something easy because you have to answer lots of questions about these. The values that we have as human beings, the kind of human beings that we are aiming to be are different kinds of human beings, obviously, depending on the different regions of the planet. What kinds of life do we want to live in different areas of the planet, in different cultures with different histories? How do we envisage our place in the planet? What kind of wall do we want to build for the next generations? All these things are involved in the same word. What levels of wellbeing or satisfaction of saying, "Well, we are living in good conditions," is not easy to define. There are a number of studies —this was done a number of years ago by Dominguez and Robin—, that have been carried out here in order to compare the degree of consumption of resources and energy, etcetera, by different populations and the degree of satisfaction that these attained when they increased their levels of consumption to satisfy their needs.

The first part, obviously, is a relation that brings to survival in which every single amount of increase in consumption produces a concomitant level of satisfaction. If I am living in a thatched hut, but I move towards a slightly better housing, with bricks, maybe, or a tin roof or something like that which requires energy, I have a satisfaction that goes concomitant with the amount of energy and resources I am using. That continues up to a point, which I will qualify as comfort.

There is a point in which this feeling of satisfaction starts flattening out: the more I consume, I'm not getting an equivalent amount of satisfaction individually. I would qualify that as a level of luxury. After one point, every single amount on the degree of consumption that I have is really giving me less and less satisfaction. This is something, you must know of these things; studies have been carried out regularly in different places with different countries in different communities,

but this is the general pattern that we have. Where do I put the point of "enough"? This is the point in which we want to be, so that other populations may also have access to energy, resources and other benefits. This is something very difficult to attain, it is different for every single country, every single –I would say region in the country–, even, but it needs to be somehow qualified. We need to reach a definition of that kind, even broadly, so we can really contribute to the chances of a more equal, fairer share of resources, of energy and of access to wellbeing.

I would suggest that the one ethical conception I visualize in one, which can encompass, on one hand, the respect for the relation and care of the environment, without which it is obvious we cannot go on —most of the problems that we are facing globally are because we are destroying the environmental matrix of this planet—, and, on the other hand, the responsibility towards members of the other species, those which are living with them now and those which will come in the next generation. That, I think, can be achieved with the four following elements.

The first one is that we really assume behaving as members of a biological species. That means that we are not only members of a given country, which may be fighting against another country, or members of a race, which may be antagonistic with another race, or members of a religion, which may be antagonistic with another religion, but, first of all, we are members of the same species. This is relatively easy to say, but it is the biggest challenge that we have as a biological species, that has generated a cultural revolution that allows to make this kind of analysis. To me, this is the core of attaining, really, not only an ethical response towards the environment, but also an ethical response towards the rest of individuals in the planet: that we must consider ourselves as products of the same process of evolution than the rest of the species with which we share this planet, and that that process of evolution occurred not in the void, not in individual species, but in ecosystems; that we need to take care of those ecosystems as the fundamental matrix for the future wellbeing of our species and the rest of the species in the planet.

That is another thing that we are not quite doing, we don't consider the fact that we are sharing genetic information with other species —

as I mentioned. We also must realize that we are altering profoundly the very process of evolution of which we are a product, and we are actually even starting to manipulate that process of evolution. These are really deep down challenges that we have to take into account, such that we have to consider seriously. As I said, I am not a philosopher, but I think we have to work together —philosophers, ethicists, sociologists, social psychologists, etcetera— to do something that really needs to be done.

If we want to go into a sustainable development, which encompasses all these elements, we need to analyze how much this concept of sustainable development constitutes a real ethics for society, and it does not at this moment. We need to really work in that sense and achieve that. This is not a means to an end, it´s a process, a tendency, one we have to follow. What kind of economic development do we aspire to achieve in that condition? An economic development that benefits only a few that have the power, the media, etcetera, in detriment to society in general, or a much better kind of distribution of the resources and the wealth? What kind of personal values, ecological, social, political, values will we have when such economic development and ethics is done and whom should these be serving?

The challenge here is to work towards defining the philosophical basis of this ethics. It cannot be done only by scientists or natural scientists. It needs to be done in collaboration with economists and philosophers and social scientists. It needs to be translated in a discourse that is convincing to everyone, because the problems we are facing are problems of personal behavior. If this doesn't change we are not going to change things in the planet at all. It needs to be a discourse that is really compelling to every single person or different discourses that are compelling to different persons in the planet.

To do that we don't have more than a few decades in front of us before the costs, the social costs, the economic costs, the political costs become absolutely unbearable. I would say that there is one more challenge for people, like you and us that work on these issues, is that we need a practical philosophy to really reach people. Not really brainy, we don't need very deep-down discourses and research that can be academically very interesting, but that has no impact on how

people behave and how we envisage our future in these decades and the future of the next generations.

d. Evandro Agazzi

Bioethics as a New Paradigm of Ethics for the Contemporary World

Independently of the question of the historical priority in the creation of the term "bioethics" (Fritz Jahr in 1927, or Van Rensselaer Potter in 1970), it is certain that the institutional development of this discipline started in the USA at the beginning of the 1970's thanks to the initiative of the Hastings Centre and the Kennedy Institute, and then it rapidly expanded in other parts of the world. Therefore, we can say that bioethics is quite a young discipline, but at the same time we must recognize that its scope has considerably broadened and includes today several domains that only a couple of decades ago were considered by several bioethicists as marginal and even alien to the genuine bioethics, so that a reflection on this historical development is certainly appropriate.

It is correct to say that the bioethical questions were originally raised by situations occurring in the practice of medicine and biotechnology, so that bioethics could be synthetically defined as the study of the ethical problems surfacing in the bio-medical sciences and their applications. But then a spontaneous question arises: since these kinds of problems have been part of the traditional medical ethics, what novelty characterizes bioethics to such an extent as to deserve the creation of a new term to denote a new discipline? The novelty is constituted by the fact that the development of new technologies and the related applications has produced a great deal of unprecedented and unforeseeable situations for which no specific moral norms or guidelines existed in traditional medical ethics. This novelty, however, must not be understood as the appearance of amazing and astonishing technological apparatuses and sophisticated practices, but in the morally relevant sense that they have put people in the situation of taking a decision and making a choice among different possible

courses of action that did not exist earlier, and this obviously entails an effort of analysis and critical evaluation that certainly reflects the adhesion of the discussants to the one or the other of more or less traditional ethical doctrines, but is far from consisting in a simple deduction from these doctrines in order to find the ethically correct norm for the new situation. All this does not entail that bioethics be at variance with medical ethics (and the fact that many bioethicists belong to departments of medical ethics or have such a chair in universities is perfectly logical), this simply means that this new discipline represents a special sector of medical ethics more or less like algebraic geometry is a special branch of geometry using algebraic concepts and methods.

Many scholars hesitate in calling bioethics a science, and prefer to speak of a domain of problems or a composite discipline, not only because the original borders of its domain of objects have significantly broadened, but also because, in order to give to a discipline the qualification of a science, certain explicit methodological requirements must be indicated that may ensure the quality of objectivity and rigor. In other words, the fact of investigating the ethical issues emerging in certain recognized scientific domains (such as medicine and biotechnology) is not sufficient to qualify a scientific bioethics; its epistemological statute must be clarified, and this entails the indication of a specific method. Obviously, this cannot be identified with the experimental method (characteristic only of certain natural sciences), nor with the logical-deductive method (typical of mathematics), nor with the historical or hermeneutical method (prevailing in many human sciences). Yet bioethics (besides the general condition of adopting rational analysis and logical rigor in its arguments, and respecting the criteria of reliable information as far as its factual statements are concerned) specifically adopts the interdisciplinary method, which is characteristic of all inquiries concerning complex realities. Indeed the situations that feed the most serious bioethical debates are precisely such due to their complexity, that consists in the multiplicity of the aspects of any given situation, whose correct understanding and evaluation requires the competent intervention of a specific discipline, based on its specific methods. But then all these "points of view" (e.g.

medical, social, economic, psychological, legal, etcetera) must be "integrated" in a final synthetic judgment; that depends on a serious dialogue among these disciplinary competences, in the estimation of the "weight" that must be attributed to the single factors in the situation considered, and finally should produce the proposal of a norm, or at least a guideline, for the adoption of the ethically correct choice. The adoption of this methodology is still rather uncommon, owing to the difficulty of overcoming the one-sidedness of the single scientific optics and attaining the intellectual openness necessary for this work.

The complexity with which bioethics must cope today has to do also with the plurality of ethical convictions present in our societies (a phenomenon accelerated by the growing globalization), owing to which we can no longer rely upon a large background of commonly accepted moral norms. This situation stimulates an effort for "justifying" the one or the other of conflicting moral judgments regarding several practices that are today possible. But this work is precisely the work of ethics and we can say that the so-called "revival of ethics" in the last decades has been the consequence of the impact on the public opinion of many issues lively debated in bioethics. Therefore, the adoption of a dialogical intellectual attitude that is indispensable for a profitable use of the interdisciplinary method should also be extended to the confrontation between different ethical positions, though this is much more difficult, owing to the existential commitment that ethical principles involve in the life of single persons.

The great majority of the bioethical issues derive from the application of the most advanced technological procedures, and, in such a way, challenge the widespread view that technological progress is in itself positive. Indeed, the "logic" of technology is that "whatever is possible must be realized," whereas the "logic" of ethics consists in saying "this is something that it is possible, but it must not be done" for moral reasons. Since such situations cover almost the whole of bioethics, we can say that bioethics is the emblematic example of a reflection aiming at finding a possible point of contact between techno-scientific progress and the evolution of the moral conscience of humankind. We speak of evolution because this maturation is required

simply by the fact that humans are today obliged to live in and of a technological world deeply different from the "natural world" that was the reference of traditional ethics.

A first consequence of this approach is the dissolution of that opposition between the natural and the artificial that still inspires several ethical and bioethical debates. In particular, one must be able to appreciate that the creation of the broad world of the artificial is precisely what characterizes human nature. The understanding of this nature cannot rely only upon biological approaches, but must include several contributions coming from the humanities and philosophy in particular, and this is precisely more and more the case in the domain of bioethics.

Traditional ethics typically considered the action of an individual and his moral obligations. In our technological world, human actions are to a large extent embedded in collective enterprises, on which the single individual has very little control. This new situation started within modern complex societies, in which individuals seldom could control and foresee the effects of their actions. Therefore the whole of the moral significance was concentrated on the intention, disregarding the unwanted consequences (Kant's ethics is the most conspicuous example of this position). Such an individualistically centered ethics cannot cope with the present state of our civilization, in which gigantic technological results of collective activities can produce long term disasters for which no single individual could be responsible. Hence, our time needs the elaboration of a holistic ethics, that considers as a whole the complex organizations that produce technological progress, and try to elaborate the concept of a shared responsibility, proportional to the degree of importance and participation of the single agent in the complex institution. By using the approach of general systems theory some progress could be attained in this direction. Moreover, this holistic ethics should incorporate the contribution of the different doctrines and traditions that are present in our globalized societies, since each has something to contribute to the appreciation of the ethical values and principles, without falling in the relativism of the everything goes, that would amount to denying the human capability of orienting that technological progress that humankind itself has produced. ◗

3.7 Session 6

Chair: David Hunter
Eduardo Matos Moctezuma: *Los estudios faunísticos en el Templo Mayor de Tenochtitlán*
Carlos Viesca Treviño: *Human Body in Ancient Mexico's World View*
Patrick Johansson: *The Aztec Cosmovision of Death before the Conquest*

a. Introduction

It is often good to remind ourselves that in the long history of humanity, there have been significant and lengthy traditions aside from our current paradigm of Western modernity and science. For tens of thousands of years, humans have faced their mortality, attempted to solve problems of survival, sickness, disease, and natural disaster, and somehow prevailed. Long before modern medicine, healers and shamans attempted to use their mythology and ancestral knowledge of traditional medicine, to understand the nature of illness and to bring to bear their worldview to everyday problems, political planning, and individual health. How are we to put into our modern context thousands of years of culture and tradition? What role does our anthropological understanding of our past as well as traditional cultures that survive, play in our modern world and our ethical considerations?

Professor Matos reminds us that for ten thousand years, humans had inhabited the Americas in complex, sophisticated, and successful settlements with vast cities, trade routes, societal structures, and complex worldviews. Moreover, indigenous traditions placed importance on the role of animals and nature in general in the human condition, and man's place in the world was defined by his relation with the rest of the natural world. Questions today about our role, our impact upon the biosphere as addressed in previous talks, were on the mind of our ancient ancestors whose religious and philosophical outlook did not ignore man's relation to nature, but rather placed this question often at the center of a worldview. Nature offered to our

ancestors everything upon which they depended, including both hostility in the form of disease and disaster, and comfort in the form of indigenous medicine and healing traditions. Much could be learned and gathered from the natural world for our comfort and care, and today we find that we are still learning of the many practical medical secrets held by the diminishing flora and fauna around us, even as we discover the uses to which ancient and indigenous cultures have discovered in unadulterated nature at their disposal.

Professor Viesca reminds us that the ancients did not separate the terrestrial from the celestial, just as they did not place man apart from nature. Understanding the human body remains a puzzle for modern science, whose piecemeal and often fractured approach to it through various systems results in more sophisticated models of each of those systems, but we haven't reached yet a holistic picture of the problem of human health, much less of complicated systems like consciousness. Before and apart from science, ancient Mexican cultures attempted in the same vein as cultures around the world to describe the body in relation to things that could be observed, and for which some predictability did exist. Namely, the stars and heavens offered observers fixed points, predictable events, and just enough inexplicable and surprising new observations to equate with changes in human health and the often puzzling systems of the body. Whereas inner space was largely unknown and unknowable due to limited tools, taboos, and the ultimate complexity of corporeal humans, the celestial could offer a foundation for models that could be applied to the unknown frontiers of health. As with numerous cultures around the world, the ways of the heavens, the terrestrial sphere, weather, and even the unseen underworld were intimately connected with the processes of individuals, families, and cultures. Placing ourselves in relation to the broader on-goings of the cosmos was a meaningful exercise in attempting to govern our conduct and to understand the nature of both our fortunes and misfortunes. It also represents a lost truth about modern science. When he was not discovering the nature of gravity, Newton was an alchemist. A *natural philosopher* at the advent of the Enlightenment was one who explored all facets of the cosmos, and attempted to understand the world as a whole, as well as

our place within it. Only modern science splits up the realms of our studies so discretely, and the ancients did no such thing. The holism expressed by placing mankind as part of cosmological clockwork has been largely lost in modern research programs. Perhaps there is yet something to be learned by viewing the cosmos and our role in it as a whole, which cannot be understood fully by specialization of the modern, scientific kind.

Professor Johansson examines the cultural role of death in pre-modern Hispanic civilizations, and death is the final result of all our studies, even in modern science and medicine, the inevitable end of all living systems including humanity. Many ancient cultures, from the Egyptians to Asia, have viewed life cyclically, and in the cyclical view of life, death is both end and beginning. Death in ancient Mesoamerican culture was certainly something for which a rich and complicated body of tradition was involved, some of which survives today in popular mythos and celebration. Death and life are intimately connected, in both myth and in modern medical reality. Understanding our ancient views of the nature of both is not only interesting but also perhaps useful from an ethical point of view. How can we responsibly fit our understanding of health and life into the inevitability of death? From the inevitable course by which our lives all lead us to our personal demise, what meaning can we create for our bodily and mental integrity? Of what importance is our personal life to the living around us and how do we assign value to the values and virtues of each of our terminal lives while they exist?

In each of these discussions we are reminded that modern medicine and the scientific worldview we have generally adopted are all quite new, superimposed upon traditions and cultures that have survived millennia despite disaster, disease, and conquest. That understanding we might attain of our ancient roots and the nature of alternative belief systems may help inform our present understanding by giving us perspective. Modern science and medicine are more successful, certainly, than any of the ancient myths we long held in one sense, that they are testable, alterable and based on experience, but we overlook at our peril the important role of culture and belief in cultures that lasted longer than ours, and that pervaded experience for the bulk of the world and over the bulk of our history.

b. Eduardo Matos Moctezuma

Los estudios faunísticos en el Templo Mayor de Tenochtitlán

En 1978 empezamos nuestros trabajos de excavación en el corazón de la Ciudad de México, a un costado de la Catedral Metropolitana y el Palacio Nacional. Ahí se levantaba el templo principal de los mexicas o aztecas, y en él íbamos a enfocar toda nuestra investigación.

Desde hace 36 años trabajamos en este lugar y hemos recuperado una enorme cantidad de ofrendas asociadas al Templo Mayor. Cronológicamente, la cultura azteca se desarrolló del año 1325 de nuestra era a 1521, cuando los aztecas fueron conquistados por los españoles y sus aliados indígenas. Me voy a referir a los rituales en los que hemos encontrado una fauna y flora impresionantes: más de trescientas especies de animales y plantas que hemos podido detectar en esas ofrendas en honor a los dioses.

Nuestra sorpresa fue encontrar más de doscientas ofrendas con diferentes materiales, las cuales son colocadas dentro de cámaras, otras en cajas hechas en piedra con objetos adentro. En las ofrendas se observa un lenguaje, es decir, no se colocaban máscaras, vasijas de cerámica o determinada fauna solamente por acumularlas, sino que se colocaban orientadas hacia los rumbos cardinales, sobre o bajo los elementos asociados, por ejemplo, el agua estaba encima de los dioses. Por un lado, teníamos una presencia de los dioses que presidian cada ofrenda, una presencia de fauna, que es muy importante porque cada especie estaba asociada a un dios. Por ejemplo, el cocodrilo se asociaba a la tierra, representaba el nivel terrestre y el águila era el ave que volaba más alto, por tanto, simbolizaba al sol.

Diez mil años antes de que llegaran los aztecas al valle de México, había una población de cazadores recolectores, pues todavía no se descubría la agricultura. El valle estaba poblado por grandes animales, como el mamut. Encontramos un ejemplar en Santa Isabel, muy cerca

de la Ciudad de México. También se encontraron huesos modificados por el hombre y usados como instrumentos, lo cual significó que el hombre ya había cazado algunos de estos grandes mamíferos. Desde el siglo XIX se conocen algunos vestigios, como el hueso sacro de un camélido al que trataron para darle apariencia de rostro animal. Toda esta fauna se extinguió antes de la llegada de los aztecas.

Pablo Martínez del Río y José Luis Lorenzo fueron dos de los grandes promotores de los estudios de la prehistoria. En el Instituto Nacional de Antropología e Historia, actualmente se cuenta con laboratorios de fechamiento, paleobotánica y paleozoología, donde biólogos y otros especialistas analizan los hallazgos.

Cerca de la Catedral Metropolitana y el Zócalo, tenemos los vestigios del Templo Mayor, las ruinas que hemos excavado desde 1978. Encontramos una ofrenda con los elementos que les comentaba y el dios viejo y del fuego, que habitaba el centro del universo: el Templo Mayor. Además en esta ofrenda se encontró, por ejemplo, un pico de pez sierra traído desde la costa, a cuatrocientos kilómetros, como ofrenda a los dioses.

También descubrimos otra ofrenda más complicada con objetos como corales, un diosecillo sentado, una cabeza de cocodrilo, conchas, caracoles y restos de peces —esto se exhibe actualmente en el Templo Mayor—; asimismo, hay ciertas especies de caracoles, y la concha nácar ya se utilizaba para confeccionar collares. La fauna también se ha representado en piedra, como esta magnífica escultura de un metro de largo, en la cual el artista prehispánico logró captar las características de esta especie. Estos resultados han ido publicados en el libro *La fauna en el Templo Mayor,* del biólogo Óscar J. Polaco, donde analiza presencias como una cabeza de puma con una bola en las fauces, codornices, águilas y garzas. Estos animales fueron colocados con su piel, porque todos sus huesos guardan una perfecta relación anatómica. Además tienen un simbolismo, por ejemplo, el águila real representa al sol porque era el ave que volaba más alto.

En *Los peces arqueológicos de la Ofrenda 23 del Templo Mayor de Tenochtitlán,* Ana Fabiola Guzmán y Óscar J. Polaco analizaron peces, conchas y caracoles provenientes del altiplano, los ríos, lagos y la costa. Hay varios estudios de Adrián Velázquez Castro, quien analizó la tipología, el simbolismo y los aspectos de su producción; es decir, cómo los aztecas elaboraban estos objetos aprovechando la materia prima animal.

Se ha estudiado toda la tecnología con la finalidad de saber cómo se fabricaba cada instrumento; hemos practicado con conchas para reproducir las perforaciones, calcular el tiempo, la mano de obra y replicar los sistemas utilizados. Las conchas se perforaban para elaboraron pendientes, pegarlas a la tela como adorno o realizar collares grandes con representaciones de diferentes animales, como uno que mide casi ochenta centímetros. Los caracoles oliva se pegaban al agave con un sentido ceremonial que aún no se conoce y se está investigando.

En el Museo del Templo Mayor, que se encuentra al lado de las excavaciones, se reabrió la Sala 6, dedicada a la fauna y la flora. Éste es uno de los pocos museos de arqueología que tiene una sala dedicada

a la presencia de flora y fauna. Los especímenes siempre van acompañados del vestigio arqueológico.

Las ofrendas que hemos encontrado son del mismo tipo: miden dos metros de largo por un metro de ancho aproximadamente. La ofrenda 126, en particular, tiene bastante material, como picos de pez sierra, vasijas de cerámica, huesos de diferentes animales y corales marinos. Al analizarla vimos que los materiales no estaban en la ofrenda al azar, sino guardaban cierto orden tanto vertical como horizontal.

Esto es una muestra de lo que ustedes podrán ver en el Museo del Templo Mayor. Podrán apreciar todos los materiales arqueológicos que se han ido encontrando a lo largo de 36 años de excavación.

c. Carlos Viesca Treviño

Human Body in Ancient Mexico's World View

The Universe was conceived in a very different way: a vertical orientation, a vertical disposition and two enrolled leaves of glass and several floors. Here you can see the creator god Quetzalcoatl and the Celestial Floors. The last three are the stars, the moon and the sun, and the next is the surface of the Earth. Downside you could see another nine underworld floors — celestial beings could go down and underworld beings, over— but the main thing is that humans are in the center.

The center was created in series of five suns, when gods took something from the floor of the Earth and build the first four floors. Then they created new human races and a new earthly home for them. Human rituals were not so good and so the gods decided to destroy each sun and build another. This is not a willful decision; it is something necessary for the cosmos' order. Each

of the five suns constitutes an era. When all the floors of the Universe have the same side as in the beginning, everything will start over.

They had a circular concept of time, a circular concept of existence. This was a very scandalous thing for Catholic friars in the 16th century and for most historians now: if you have the patience to wait millions and millions of years, all the things of the universe will repeat in the same way, in some future era all of us will be in the same place, with the same things, with the same problems.

The first sun was destroyed by wind and men were turned into monkeys. Human beings in the fifth sun were created, in Mayan legends, from *maize:* our body was made of maize. In Aztec, Teotihuacan and Toltec legends the human body was made from the ashes of our ancestors and the blood of Quetzalcoatl. Some of the spirits like *Tonalli* are in one of the celestial floors, and Tlaloc's in a tree called *Chichicuáhuitl*, the tree of the breasts, taking milk and waiting time to come down to the Earth and be complete human beings.

They think humans have an astrological body. Like in Ancient Mesopotamia where they divided cosmos into twelve parts with the Zodiac, the ancient Mexicans explored the stars, planets and divided celestial space in twenty spaces. Each of these is represented with some animals that you can see in Templo Major. Each animal corresponds to a body part. The heart was considered the center of body, thought, emotions and life. The heart governs the body. The left foot, jaguar, is Tezcatlipoca, the son in the underworld and represents black magic, passions, the destroying powers in this fifth sun. The next sun in the next era will be constructed by the underworld sun and then all the things will be in the opposite way.

This astrological body provides several possibilities. The possibility to have a destiny comes from the day of birth. A specific part rules this day and represents the temperament and the kind of life. They also have an historical body. This comes from *Historia Tolteca-Chichimeca,*

a document from the 16th century. It represents the uterus of the earth in the form of a flowered cave inside human peoples' lives. It represents a life in caves, after that hunters are depicted, re-collectors, and then the agricultural culture, and finally the big imperial cities like Teotihuacan, Tula and the Mayan cities. People go in and out, reproduce, and populate the Earth —it is a very important concept of the historical presence of human beings.

Also human beings need access to the heavens, to other parts of the Universe and this is possible in two ways. In one way, people are selected by gods; for example, when a thunderstorm comes and people survive, they acquire specific possibilities to be in contact with gods. The other possibility is the shamanic experience with hallucinogenic plants. I have located about ninety different psychotropic hallucinogenic plants coming from ancient Mesoamerican territory. This is a beautiful representation of an actual shaman, by the artist David Silva. It signifies the flying shaman, the possibility to transport to every part of the Universe in a spiritual body.

They didn't practice autopsies, neither studied anatomy, but they knew very well the external parts of the body accessible to heal the wounds. They could distinguish the internal body parts. For instance, the *Florentine Codex* is a document that has a lot of pages with anatomical lists of body parts and descriptions about their relationship with muscles,

bones, veins, but mainly the function of each part. Also a pathological body that receives the inferences of other parts of the world —the universe's upper floors and underworld floors— can be damaged.

They had concepts developed in a medical system, a vast knowledge of lesions and illnesses, and a particular classification that divides the body in two parts. First, the diaphragm represents the Earth and its surface; over the diaphragm, you have all the floors of the heavens and under the diaphragm the floors of the underworld. Secondly, the human body is a microcosmos and the heart represents the sun, the center of the body, and the fusion of the powers of the upper and under worlds: the equilibrium. Equilibrium is health, and the loss of equilibrium involves the possibility to become more hidden or colder. Cold is hidden in the underworld and changes the body in the upper world expressed as fever or coldness. Remedies come in the same way: hot, cold or warm. In this system you have a precise possibility to make diagnosis from direct clinical explorations, from astrological interpretations and physiological interpretations from cold and hot illnesses.

Also, they had a lot of procedures like enemas, bandages, and the possibility to reduce fractures or luxations. The official history says that in the 16th century they found a reference to a surgery made at least two hundred years ago. But in Sierra Norte, Puebla they found one skeleton from eight hundred years ago with the same procedure, a medullar reconstruction of fractures by surgical procedures.

They had the concept of a sacrificial body. The human sacrifices were considered by the Spaniards as barbaric procedures, they were scandalized by it. The sacrifice was not a capricious thing, it involved a ritual to offer the heart and bring the possibility to maintain the sun's life. If the sun doesn't have food, it will die and the central part of the universe will also die.

In the last times of the Aztec Empire, there was an excessive practice of human sacrifices. The inauguration of Templo Mayor had over 25,000 men put to death. Each sacrifice represented a god. These men were prepared, once a year someone died to Tezcatlipoca. That person needed to have high social quality, he was selected for his capabilities and was treated like the god in Earth. After that he was sacrificed representing the passing of Tezcatlipoca from the Earth to the places he went.

They also had cannibalism. Not everyone did it, only sacrificed and deified people: it was a pre-Hispanic communion with the flesh of god. But also, every one of us could have offerings of their own blood, blood coming from the tongue, penis and legs. This was offered and burned converted into food for the gods and spiritual powers that maintain the Universe.

Finally, this pre-Hispanic civilization believed in a moral body with moral qualities or perversions. Fray Bernardino de Sahagún asked Indians: "Who is a good doctor?" And they answered explaining the abilities, properties or characteristics of a good and a bad doctor. In this way a good doctor needs to know the powers of the underworld to have complete power. Traditional healers in rural areas have three possibilities: a good healer that only cures, a bad healer that prefers to provoke bad things to people, like death, and the most powerful for them: the one who can produce evil and cure. The healer needs to know who will receive the evil or the cure. During the birth of children, midwives invoked astrological bodies, they brought *tonalli* to the baby and told him his destiny. The moral body needs to be cultivated, educated with exercises, texts and signs to become a full woman or man.

For them, having a face and a heart meant you are a complete person. Also when someone overcomes a big danger he becomes a better man and will live many years. The wisdom of old people is the best example of a moral construction. We have many types of bodies, and there're also symbolic bodies that let us understand more about ancient and modern cultures.

d. Patrick Johansson

The Aztec Cosmovision of Death before the Conquest

In terms of bioethics, an appropriate approach to death in pre-Hispanic times would require a whole congress. Among Aztecs, man was considered a "creature of death" in the sense the German philosopher Martin Heidegger attributed to the expression. We can find their vision of death, for example, in the different parts of the Netherworld or *Mictlan*: the House of the Sun and the House of Tlaloc, or the funeral

rites like the Day of the Dead and human sacrifices, as an offering to Mother Earth and Mother Death. In the House of the Sun, people were sacrificed to the sun, *Tonatiuhichan*. Here you can see Mictlantecutli, the god of Death, cutting some umbilical cords of what will be someday dead. The ball game was also a ceremony where people were beheaded.

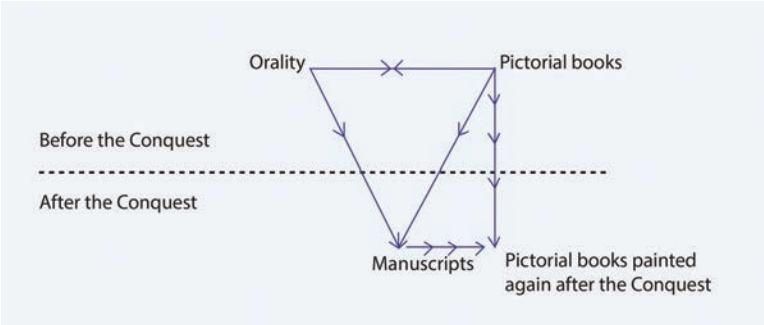
There are four places to go after death, but Sahagún didn't mention the fourth because they didn't match the Christian vision of death. The fourth place is *Cincalco*, the house of maize. Something very interesting happened to Cortés, he once asked the high priests: "Where can I go?," and the answer was that "there are four places where you can go: *Mictlan*, the Netherworld; *Tlalocan*, the place of the rain; *Tonatihuichan*, the place of the sun; or *Cincalco*, the place of the house of maize." He chose *Cincalco*, even though he couldn't go.

The vision of death for children is also interesting. When a child had less than three years and didn't eat maize before, he was considered lacking a body. A dead baby like this would go to Mictlan. He was considered a shoot of maize and would go back to earth —there was no ritual for this. Three year olds who died went to Chichihualcualco, the tree of breasts.

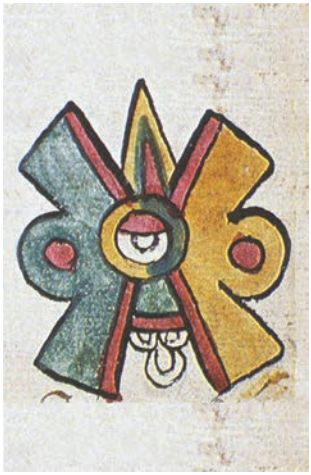
Epistemological and heuristic considerations

I am going to talk about the Aztecs' vision before the Conquest. In the 16th century the Spaniards just wanted to evangelize the natives. To do it they had to know more about their culture, so they collected information. The problem with the pictorial books is that they didn't understand them and wanted to use them as tools to turn natives into Christianity.

We have many Spanish interpolations. I will read some phrases in Nahuatl and then the Spanish translation in English: *Zancen ye nicantlalticpac*, which the Spaniards translated as "only once here on Earth." This is not a proper thought of the old Aztec people, because



Spaniards wanted to change their idea about the importance of the course of Death. They wanted to convince them that there was only one stay on Earth, and it was impossible to come back. The authentic indigenous texts say: "*Ca iuhmitoayah: in ihcuactimiquih ca amo nellitimiquih, caye tiyolih, ca ye titozcalía, ca ye tinemih, ca tiizah*," and the translation is "Thus they said: when we die, we don't really die, we still live, we still grow, we still exist, we wake up." In other sources: "*In yehuantin in axcannemih, occeppanemizqueh, yezqueh*," which means "Those who leave now will live again, will be again." This is very important when we are reading the sources, even if they are in Nahuatl. Many times we don't have the right information because the Spaniards made interpolations in Nahuatl texts to change the natives' idea of death. As you could see in the last text, the real thought for me, death comes several times on Earth and there is a return on Earth.

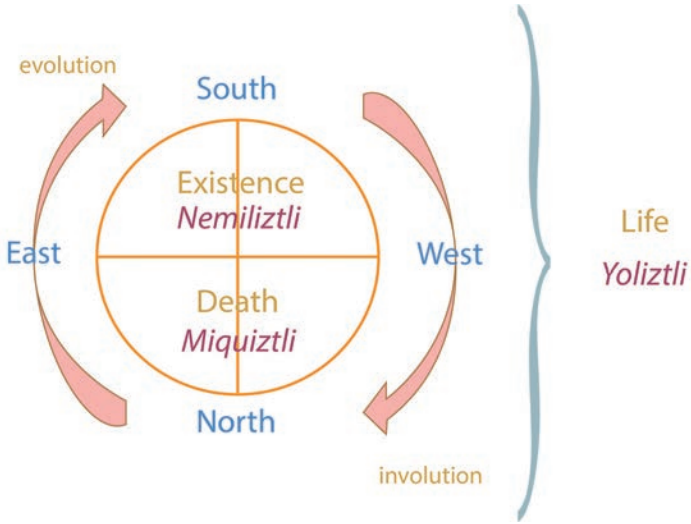


The expansion of the world and the origin of death

It is important to recall the different eras: first, the world of earth; then a world of wind; another one of fire; and finally of flood. The most important thing is in the center: the god of the Fire (Huehueteotl) and the god of Sun (Tonatiuh) that are superposed. Here you have the different eras, the sacrifice

and the heart. In this picture you can see Ollin, the concept they had of life. There wouldn't be life if there were no movement. You have the four places, the four eras, the four circles of the ball game, and the four matters: fire, the rabbit on the right represents earth, water and wind. In the middle a Starry Eye that's also death. Death is just an access of life. And in the very middle you can see Huehueteotl, the god of Fire.

There is a myth that says one fire was created by God for Nanahuatzin and Tecuhciztecatl. Two gods jumped into the fire, and became two suns, not one sun and the moon. And with two suns, life was impossible. They passed from darkness and chaos to light, but there was no movement. What the god said was "light's time, *Ma timuchintintimiquican.*" Biological life was considered as a part of life. We should not miss "*Nemiliztli, Miquiztliihuan Yoliztli," existence, death and life*. This is the main point of my presentation, that we should not oppose, as we do in Western world, Life and Death; but Existence and Death, because both of them are life. Metaphorically, we could say that existence and death were respectively the systolic and diastolic phases of Life's heartbeat.



In general, maps in the Aztec world are oriented to the East. This is not a Euclidean world: horizontality and verticality are together. I chose

to have the verticality of the world, the sun at noon is in the South, dying in the West and during death he is crossing and reappearing again in the next morning and the next life, talking in terms of human life.

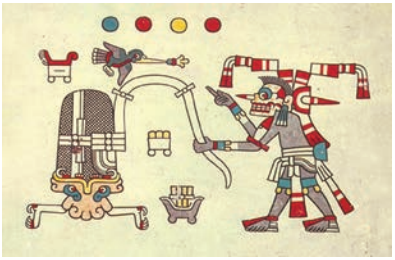
You have an evolution, involution and existence, the *nemiliztli* and the *miquiztli. Nemiliztli* is a word composed of *nemi* or *nehnemi,* which means to walk, to wander, to go, to advance. *Nemiliztli* is also the way of thinking, it means to think. It is very interesting to see that *nemi-* plus the suffix *-lea,* and the morpheme corresponding to the substantive *-liztli* becomes "thought." When you are existing you think, and when you are dead you are being thought. That would be the message of all this. In this way you have existence and death, systolic, diastolic heartbeat, and this is life *yoliztli.*

The creation of human beings in Mictlan, the Netherworld

On the same way of thinking, considering Existence and Death as life, it is interesting to recall that human being was created within the Netherworld. Quetzalcoatl went down to Mictlan and asked for the bones that Mictlantecuhtli, the god of Death, was keeping. This is a very long myth, but I think it's important to recall the penetration of Mictlan by a celestial god that provoked the creation of man. Mictlantecuhtli said to Quetzalcoatl: "In order to take away the bones to Earth you have to blow into your shell." Quetzalcoatl blew and the luminous sound of the shell penetrated into the ear of Mictlantecutli, which represents light in darkness, and this sound fecundated Death —that's an interpretation. In the funeral rite a shell blows all the time, and it is not only to have music, also because mythologically they did believe the sound of the shell would fecundate death.

The *Florentine Codex* states that when a woman was about to give birth, a midwife said: "*Ocyohuayan, oc Mictlan...;*" "He's still in the darkness, he's still in the night, in the Netherworld, in Mictlan," referring to the child. The midwife said that a

pregnant woman's womb was Mictlan, which means the realm of Death. This is very important to mention. Here you have an illustration. Quetzalcoatl is on the right, blowing into the shell that is going to be the volute: the sign of sound and words among the Aztecs. You have also the prisoner, that's a human being related to the sun.



When somebody was dying, he was buried in *toka*, which in Nahuatl means to sew and to bury. When someone died, Tlantecutli would eat the body. As I said before, when a child had more than three years and started to eat maize, he had a body of maize. And when he started to die, Tlantecutli would eat his body during four years, to have the white bones without flesh, in order to bleed on them the sacrificed's virile member that would fecundate death. This is very important because you start to die in the west of your life, like a setting sun, and you finish your death four years after, when Tlantecutli has eaten your body and has left only your bones.

In this image from *Codex Laud,* you have Tlaquimiloli, the pack of the disease, and Tlantecutli eating the body and soul of a hummingbird warrior suckling a flower.

Ximiximati, "know yourself"

When you talk about *Ximiximati,* which means you have to know yourself, it might seem like something Hellenic. Quetzalcoatl was a god but also a man, and he didn't know he was mortal until Tezcatlipoca came and showed him his mirror: he saw himself completely. When he was dead, he had to go to Tlillan-Tlapallan to go away, be burned and incinerated.

At the beginning we said that fire was a center of the *axis mundi,* and when kings and lords were dying they had to be incinerated; they were burned, because fire in death means you were regenerated. The text in Nahuatl says, "*Ce tlacatlompatlapia, ye huehuetlacatl,*" that is: "You will to go to Tlillan-Tlapallan," a place in the coast of Mexico where you are going to be burned. They were saying:

Ce tlacatlompatlapia, ye huehuetlacatl. Anmononotzazqueh.
Auh in ihcuactihualmocuepazocceppatipiltontlimochihuaz

That means "there's a man there in Tlillan-Tlapallan, an old man, you will talk to him, when you come back you will be a child again."

The regeneration of time in death

In the Western world, we die because of time, but in the pre-Hispanic Aztec world, time also had to die. There was a ceremony every fifty-two years, because they believed the movement of the world and the movement of the sun were turning all the time; the sun was tired and Time had to die to be able to continue. In this ceremony they represented the death of time, by burning fifty-two stocks of cane.

To end my talk I want to say *Ca xochitl in tlacatl; cueponizancuetlahuia*, meaning "Man is a flower, he blooms and he withers." ◗

3.8 Session 7

Chair: David Koepsell
Adolfo Martínez Palomo: *Disability and the Universal Declaration on Bioethics and Human Rights*
Carlos Alonso Bedate: *The Triple Helix for a Global Health*
Florencia Luna: *Reproductive Rights; still a Pending Issue in Latin America*

a. Introduction

Medicine is typically thought to concern issues of illness and disease, and medical ethics thus centers upon such issues in both practice and perception. But there is more to the field of medicine, and much more

to human infirmity than passing illness. Professor Palomo reminds us of the role that States, institutions, and ethics play in ensuring some justice for the millions worldwide who are not sick, but rather disabled. Disability is a tricky category for bioethics, and there has evolved a complex net of social institutions not only to deal with disabilities themselves, but also to ensure that the manner in which we regard those with disabilities is just. The disabled are typically construed as a vulnerable population and thus to be treated with particular care in clinical research, yet there is a current of modern research that considers the problems of "ableism" as a strong undercurrent in our society, preferring the abled over the disabled in speech, politics, and other social phenomena.

One of the overarching problems of modern liberalism is that of the tension between the values of freedom and equality, which according to the great debate in the 20th century by Nozick and Rawls, cannot be resolved without some compromise of one value over the other. Some prefer to value freedom above equality, and others to place the two in the opposite hierarchy. The way we structure our societies reflects this tension of values, maximal freedom, for instance, would regard freedom of movement and migration as a paramount value, but the reality of social migrations is that they often result in inequalities. Whether and to what extent these inequalities arise to the level in injustice is up for debate, but the clear trend in the 20th century toward urbanization has resulted in not only a more stratified society with apparently fewer resources to spread to more people, but inadequate and potentially unjust access to basic health and services for the rural poor fleeing to the cities. Just as with problems of ecosystems and biospheres, migrations of populations raise concerns of human rights, access to care, and medical ethics that we must grapple with, even as we expand to typical scope of our study.

Professor Bedate recognizes that the institutional structures of modern medical research and clinical practice result often in unjust distribution of benefits and burdens. The distributed nature of scientific discovery, entrepreneurial development, and eventual commercial marketing of new pharmaceuticals is not efficient, nor is it necessarily terribly effective at bringing life-saving, necessary drugs to market, nor to populations that require them. Altering the structure of the current arrangement may be in order. Basic scientific discovery suffers lately at

the whims and exigencies of governments whose coffers and public will for basic expenditures in science vary according to other pressures. Commercial drug development, which takes the basic science of newly identified molecules and tests and tweaks until some perceived, possible medical benefit is noted, runs the gauntlet of national and international clinical trials regulations and procedures and eventual approvals, more often than not fails. Finally, new diseases, orphan diseases, and critical drugs necessary to fight emerging plagues or under-represented but critically ill patients, suffer in the process. The current structure, multiplied over the various jurisdictions and localities, all with their own political exigencies and pressures, cannot be adequate to deal with the drug needs of the future. The triple helix model that Professor Bedate discusses is an alternative approach, meant to address the conflicts in the current model, and to achieve the ultimate goal that all these institutions are meant to address: health. The academy, the State, and commercial institutions must be wrangled into new arrangements to meet the problems of modern disease in the international milieu. Without some international agreement on how these relationships can be better governed, our ability to deal with emerging threats like Ebola (as we have seen this past year) is in jeopardy.

Finally, Professor Luna addresses another area of entrenched injustice, the inequalities between the genders and their expression in matters of reproductive health. Worldwide and to a large extent, the power imbalance felt by women is reflected and accentuated by laws and regulations regarding the accessibility of reproductive health information and choices, including importantly, access to abortion. Only lately societies around the world began to provide more equal access to reproductive choices, but in much of Latin America that progress has been slow, as in developing countries around the world. Partly due to religious history and influence, equal and often medically necessary information and treatments are not easy to find, or remain too costly for the poor, minorities, and women. This is of special importance in the realm of reproductive health. Often, as a result, illness and death are the result as women without alternatives in the public medical sphere seek solutions that are neither safe nor regulated.

Complications from illegal abortions and black market solutions to inadequate public commitment to matters of women's health and

reproductive choices unequally affect the poor and mortality among these populations is a matter of medical justice. Governments who fail to recognize the still present treatment of women's health issues, just as with the disabled, migratory populations and others whose social status keeps them subjugated, fail to address medical justice just as surely as those who disrespect the treatment of human subjects.

These speakers address important and unfortunately still abundant issues of social justice reflected in our clinical practice and scientific, academic, and regulatory frameworks. Justice is one of the bedrocks of bioethics, and it remains important to recognize the role of this value beyond the area of human subjects research, but in the broader realm of human health in general.

b. Adolfo Martínez Palomo

Disability and the Universal Declaration on Bioethics and Human Rights

Esto no va a ser una presentación para expertos en el tópico, sino para un público general que no esté familiarizado con el tema de la discapacidad y la bioética; se trata de generalidades.

Vamos primero a los antecedentes en los que hemos trabajado desde hace ya un buen número de años. El año próximo se conmemorarán diez años de la Declaración Universal sobre Bioética y Derechos Humanos, de la UNESCO, un proceso muy complejo, muy interesante en el que participamos durante varios años, que finalmente, fue aprobado por aclamación por todos los estados miembros de la UNESCO, lo cual fue una gran sorpresa dado la dificultad del tópico y la de generar consensos entre culturas tan diferentes como las que se encuentran en nuestro planeta.

Varios de los artículos que se encuentran en esta Declaración Universal sobre Bioética y Derechos Humanos tuvieron particular interés en Latinoamérica y México; uno de ellos es el que abordamos en México, sobre responsabilidad social y salud, en 2009 concluyó la revisión de este tema justamente en la Ciudad de México.

Hay dos artículos de esta declaración que son particularmente interesantes y que tienen que ver con los dos temas que vamos a tratar.

El primero de ellos, Artículo 14, se refiere a la responsabilidad social y salud; impulsado fundamentalmente por nuestros colegas latinoamericanos quienes insistieron en que este artículo apareciera en la Declaración, una de buenos principios pero extraordinariamente difícil de llevar a la práctica:

- Acceso a atención a la salud.
- Acceso a niveles adecuados de nutrición y agua.
- Mejora en las condiciones de vida y del ambiente.
- Eliminación de la marginalización.
- Reducción de la pobreza y del analfabetismo.

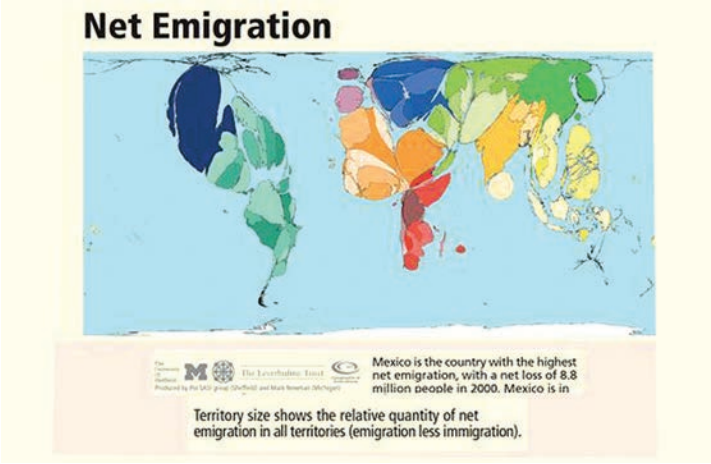
El otro es el Artículo 8 sobre respeto a la vulnerabilidad humana y la integridad personal. Éste es particularmente importante en el tema de la discapacidad.

Esto se ha trabajado, y desde el año anterior, los organizadores de este Congreso, el doctor Ruiz de Chavez y sus colaboradores, organizaron un simposio internacional preparatorio a este Congreso, donde presentamos los resultados preliminares del trabajo que hemos venido realizando con el grupo MOST México, de UNESCO, el cual coordino.

El MOST significa la Gestión de las Transformaciones Sociales en español o *Management of Social Transformations* en inglés. En México lo que hemos venido trabajando en los últimos meses es justamente —los temas de bioética, migración y bioética de la discapacidad.

De lo primero vamos a hablar muy superficial y rápidamente, aunque sea un tema enormemente importante para México.

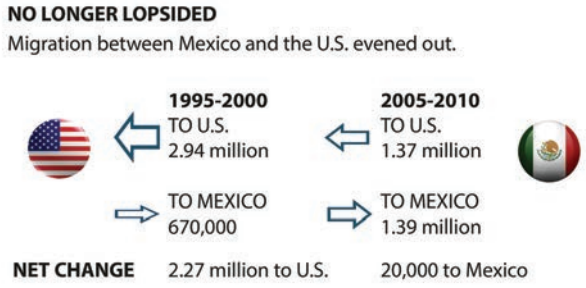
En el mapa, se observa la emigración, es justamente México, el país del mundo que en el año 2000 tenía el mayor número de emigrantes. Hay muchos otros países de Centroamérica, Sudamérica, Asia, países africanos, Estados Unidos y Canadá que ni siquiera aparecen en el mapa; si esto lo hiciéramos con cifras actuales la desproporción sería posiblemente mucho más grande.



El problema de emigración de los mexicanos es importante, pero también el de los centroamericanos que pasan por México tratando de llegar a Estados Unidos.

Este hecho se ha revertido en los últimos años, lo que en el año 2000 era francamente una emigración hacia Estados Unidos, actualmente a consecuencia de la crisis económica en Estados Unidos y del reforzamiento negativo de los programas de migración para los mexicanos, esto ha cambiado radicalmente.

Para el año 2000 era prácticamente igual el número de mexicanos que salía de Estados Unidos y el número de mexicanos que tenían que



Sources: Mexico national census; Pew Research Center; Mexico Interior Ministry

regresar. Todo ello representa problemas de salud, y finalmente de bioética de migración.

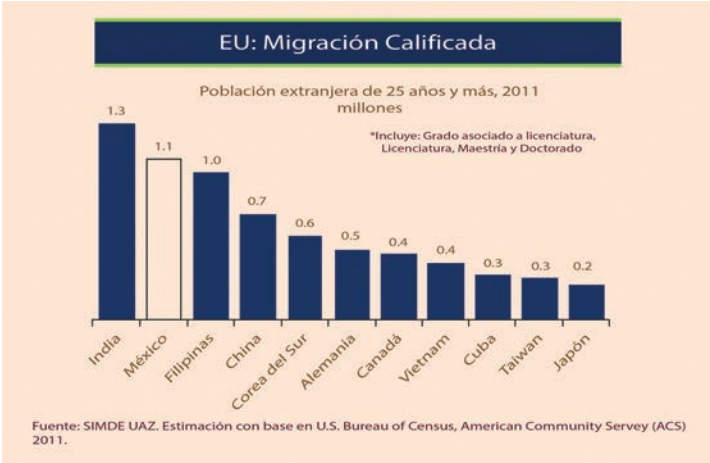
Justamente ahora, hay un debate muy grande en que el presidente Obama de Estados Unidos, está teniendo dificultades muy grandes para llevar a cabo la reforma migratoria que había prometido hace ya tiempo y que parece que no va a pasar tal como hubiera sido deseable.

Una de las actividades de estas reuniones que ha organizado el doctor Manuel H Ruiz de Chávez, ha sido justamente una sobre *Bioética, migración y salud*, donde se discutieron algunos de estos temas a profundidad.

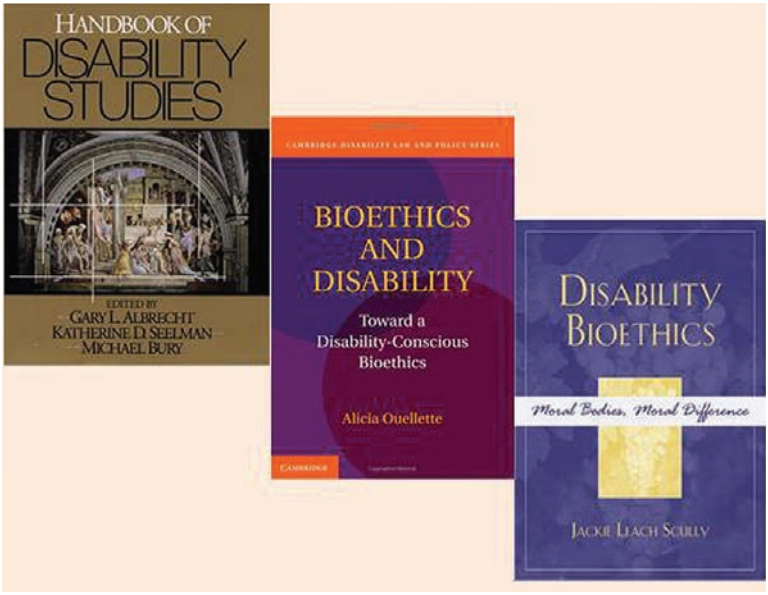
En el grupo de MOST nos interesan los dos aspectos: la migración de la gente desprotegida —los que buscan condiciones mejores de vida, tanto económicas como sociales—, pero también la migración de mexicanos con formación universitaria, ya que cada vez más están emigrando hacia Estados Unidos, Canadá, en ocasiones, a Europa, y que representan una pérdida, un sangrado muy grande, una si se quiere llamar "fuga de cerebros."

Algunos de los datos del MOST México, que obtuvo el doctor Raúl Delgado Wise, experto en este tema, son: para 2011 en México había cerca de un millón de mexicanos con grado de licenciatura, maestría o doctorado.

El porcentaje de mexicanos con doctorado que están fuera de México porque han emigrado y que trabajan en otros países es enorme.



Esto es un problema muy grande, porque México los entrena, les confiere la beca, les da la formación, y después emigran. Son centenares de miles de mexicanos, no estamos hablando de unos cuantos. Un país con escasos recursos, como México, está continuamente perdiendo a la gente que más necesita para mejorar sus condiciones de vida.



Vamos a pasar al otro tema: la discapacidad. El análisis de la Declaración Universal de Bioética de la UNESCO en relación a la discapacidad, sólo puede ser realizado por expertos; por consiguiente, hemos solicitado a dos expertas internacionales, la doctora Jackie Leach Scully y la doctora María Casado, revisar cada uno de los artículos de la Declaración Universal de Bioética y Derechos Humanos y ver en qué medida se relaciona con el problema de la discapacidad.

El tema de la discapacidad tiene un análisis académico muy sólido—hay instituciones dedicadas a este tema—, sin embargo, el problema es cómo llevar a la práctica lo que la academia considera conveniente para mejorar las condiciones de aquellos en situación de discapacidad.

Por ejemplo, una de las iniciativas de hace ya más de diez años, de la Unión Europea sobre enfermedad, discapacidad e inclusión social es la *European Foundation for the Improvement of Living and Working*

Conditions. Lo interesante es que a pesar de que están tratando a fondo el problema de salud pública y discapacidad, no se menciona a la bioética en todo este documento importante, muy bien fundamentado.

Lo mismo pasa con un documento mucho más reciente, de 2013, en el cual la UNESCO y varias instituciones, inclusive, instituciones privadas, no solamente organizaciones internacionales, analizan el problema de la discapacidad y cómo puede encontrar un remedio, al menos parcial, pero muy importante y moderno, en las técnicas modernas de comunicación.

En este trabajo se menciona que lamentablemente la discapacidad no fue reconocida entre las Metas del Milenio y, por consiguiente, no tiene seguimiento. Insisten sobre el hecho que en las tecnológicas de la información y la comunicación pueden tener un campo muy importante para abordar el problema de la discapacidad.

Se estableció el año próximo para el cumplimiento de las *Metas del Milenio*. Lamentablemente, los expertos aseguran que no se cumplirá prácticamente ninguna, entre las cuales se olvidó incluir a la discapacidad.

Pero hay otros programas internacionales, como el de la Organización Mundial de la Salud, un estudio muy importante dedicado a definir qué es discapacidad.

La discapacidad durante muchos años se consideró un problema médico, sin embargo, es fundamentalmente un problema social; los expertos mencionan que la discapacidad la genera más la sociedad que el individuo que la sufre.

En este sentido, esta clasificación internacional de la Organización Mundial de la Salud es relevante porque toma en cuenta la enorme variedad de alteraciones que pueden considerarse una discapacidad, lo cual incluye la discriminación por género, por color, por raza.

Es pues un tema extraordinariamente importante y el cual organizaciones internacionales como la OMS están tomando en cuenta.

México fue el país que inició la Convención sobre los Derechos de las Personas con Discapacidad, la cual tiene un carácter vinculante. Inmediatamente, los países latinoamericanos empezaron a reunirse alrededor de México. El propósito fundamental es asegurar todos los derechos fundamentales de las personas que sufran de discapacidad y promover el respeto a su dignidad inherente.

Existe una posibilidad de que esto llegue a un nuevo programa de Naciones Unidas, que son justamente las Revisiones Periódicas Universales, hechas por la Oficina del Alto Comisionado de Derechos Humanos.

Los derechos humanos abarcan una gran cantidad de aspectos, nuestra sugerencia es que la discapacidad sea incluida, de forma que cada vez que se hicieran dichas revisiones, se pudiera evaluar periódicamente cómo se va avanzando en eliminar o reducir los problemas a los que se enfrentan las personas con discapacidad.

c. Carlos Alonso Bedate
The Triple Helix for a Global Health Care

Estoy verdaderamente impresionado, porque nunca he hablado ante un auditorio tan enorme, no sólo extenso, sino extenso en conocimiento; pero trataré de hacerlo lo mejor que pueda.

Evidentemente para mí es un gran honor estar aquí, hablarles de algo que en los próximos años o las próximas décadas va a tener muchas problemáticas y va a ser muy discutido.

Voy a leer en inglés, porque es una ponencia que me encargó la Unión Europea, y se va a publicar dentro de poco, y lo he tratado con el título de *The Triple Helix for a Global Health*.

When dealing with the aspects of development of therapeutic products, against certain diseases and particularly against infectious

diseases. The first thing we have to say is that these diseases kill approximately 17 billion people every year and that if it is most likely that the amount of people who would be affected by any civil form of the diseases has to be multiplied by ten. The task of research and development and the financial requirements needed to carry out the task to lower these numbers and eliminate these diseases, is an ethical and justice imperative; nothing else than justice and ethical imperative. In fact, life and health care are the most basic human rights. Yet, disparities within countries continue to grow, threatening political security and global stability due to the internal inequalities and external outfighting and internal infightings. Poor countries bear over 80% of the global burden of disease in disability adjusted life years. In spite of the intense effort that has been made in the last decades to solve global health problems in developing economy countries, particularly infectious diseases, the amount of money of NGO's, governments and foundations have made available for such a name, there's still much to be done. In fact, it seems that migrations and what follows after migration means infectious diseases will remain a dominant characteristic of internal health programs in the 21st century.

Second, establishment of appropriate levels of confidence. Regarding the development of health-related products and health trials, one of the fair requirements for success, for any kind of success, is to create a fluid relationship between the suppliers of research and those that receive the benefits of research and to establish appropriate level of confidence. The lack of a perceptive approach between the promoters of research and development, and the receiving countries is one of the fundamental reasons why high degrees of misunderstanding have frequently appeared between populations. The distrust can abort the process of development that goes from the identification of a product to its application. This means that the research activities should not ignore the characteristics of the area where the resulting product is going to be applied. If the receivers of the product and research are not involved in the RND programme, that least development of the pharmaceutical product most likely and this is important, most likely the entire developmental process is not going to arrive to any important cities happening now. Therefore, alliances between agents involved in RND in regulation, together with those involved in clinical

testing are absolutely needed. Otherwise, nothing is going to be achieved.

Third proposal. I am fully aware of the administrative and financial problems that this suggests and implies but I believe that even theoretically, there is no other real alternative and we have to be convinced of that: there is no any other real alternative. A particular product coming from research process has a positive or negative value only when the utility test has been performed. Not before. The question, therefore, regarding the development of the drugs in clinical tests, is not whether or not it is an imperative of justice to arrive to an agreement regarding the availability of the products of the patients before the test is carried out, but whether the test populations have the right to partake the benefits of the research. In fact, they have contributed to determine whether the product has value or not. I am aware this question is complex and not easy to formulate and resolve, but I believe that this is a justice and ethical imperative.

Benefits sharing is crucial point to discuss and to guarantee that the receivers will have access to the research products. If we avoid talking about this issue, the consequence is what we already are seeing. Developing economy countries and above all, under developing economy countries have in fact very limited access to pharmacological products, whose effectiveness has been sometimes verified in their populations and not before. The added value is due to the tests in this type of population. Why, if they have contributed to bring to the product a high value, don't they partake of the benefits of the product? This is ethical imperative. If the efficacy trials lead to development, it seems to me that the value determined by the efficacy test should be integrated in the RND process final value.

In the past, the clinical test benefits were considered to a large extent as being the results of a service contract or a safe way to compensate the targeted population for the work done. The trends now are that this type of contract will not be accepted in the frame of developing countries in the near future. It may be that poor countries will be the only ones that will accept this type of contract. The reason is that they are forced to do it because they do not have any other choice. However, the question is, is it ethical to take advantage of that situation? Moreover, it is necessary to control at all cost that clinical

trials are used as instruments to collect biological sample materials as it is really happening now.

It is known that with the technology we have at hand, human samples could be a treasure to complete phase two trials and an alternative in the use of humans to ratify the proof of consent. In the past, clinical tests in developing countries concentrated in large phase three studies that included phase two. This was very costly. At present, pharmacological companies try to perform phase two studies and sometimes phase three, steps to reach the proof of consent quickly, so they can determine whether to move forward. This means that in this scenario, phase three clinical tests are going to decrease in number with terrible consequences.

Fourth, the generation of complex health-related problems. It appears that the generation of new global health-care related products will exceed at least an order of magnitude. The sophistication of the effort in RND, has been needed to generate the product we have now, not only because of the technical and scientific requirements, but also for administrative resources, regarding safety regulation, registration, requirements and clinical testing in different age and genetic populations. For example in USA, from 2000-2005, the complexity of clinical trials, as measured by the total number of procedures that need to be performed increased by 49%. In the rest of the world, the complexity increased higher, by 60%. The clinical procedures to develop pharmacological products in the future seems to be more complex than the ones required until now.

This is an important point to consider, if out-of-hand complexities are required for the performance and management of RND, the actual engagement of scientists in innovation can be paralyzed. The question yet to be answered is whether the same procedures should be required to be performed in all environments. I will give you an example. If vaccine trials against HIV or malaria have been carried out and the results have been negative by reasonable indication vaccine could be effective in all the population. Where the pressure of infection is lower, should the clinical testing of this product in this population be abandoned, as it's happening now? It could happen that potentially efficacious products could be discarded because they have not shown to be efficacious in a particular environment, while they may be efficacious in other populations. It is happening.

Fifth, the constitution of alliances and institutional governments. Since neither public nor private finance or not-profit instruments can tackle the problem of improving the international state of public health care alone, many organizations dealing with international public health problems have anticipated the creation of a partnership with the private sector. In fact, many academic institutions have formed groups with the industry to take forward research activities to develop therapies, fundamentally vaccines. The World Bank favours the initiative mediating the creation of a partnership between the public and private sector. Is pharmacy to serve as a bridge between industry and intergovernmental organizations in order to obtain a global framework for health care on the basis of mutual agreement and an explicit definition or task? It seems to me that alternatives to these alliances and efforts do not appear to exist.

So far, *ad hoc* and temporary alliances between individual institutions or industries have been established. In the future, these alliances should be expanded and lead to stronger and more stable interactions, not only between research groups, as it is happening now, but also between such groups and the teams that lead the assays and control them. Innovation is increasingly likely to come out of individual performances or even from a rather small institutional sphere, within universities or industry. It seems, therefore, that the location of RND has reached the health-care system. This is the real problem.

Post-academic industry and State commitment. The real problem at present is that we do not the rules that govern the cooperative alliances between academia, industry, foundations and governments. It is common place that cooperation is positive and leads to innovation, since it they may develop emerging mechanisms that are the products of collaboration and synergy; but it should also be accepted that the relations between these sectors are usually ambiguous and driven by necessity, rather than by the real belief in their efficacy.

How institutions with different interest, values and global visions can converge in promoting a common good? This is a real question and we have to answer. Who established criteria to assure transparency along the processes of these alliances? The answer to this question certainly leads to a change in the way international research is being

carried out. Other underlined theoretical questions refer to the unclear definition of what it means to be a public entrepreneur entity, in particularly, it is not easy to define who establishes the objective and decides, in case of conflict of interest, between academy, industry and government. Due to the economical and the scientific nature of the objective, additional political dimensions are added. Politicians always want to gain.

Among those governance and objective definitions, which kind of leaders did control the participation of different sectors and promote transparency and efficacy? The task is difficult, but it seems to be clear that collaboration between social agency with public and private finding is the *sine qua non* requirement for the efficacy of the development of global health-related drugs and instruments at their international levels. As indicated by the Pan-American Health Organization, the control of the program of global human health has to achieve a balance between formal and informal mechanisms of governance and between market forces and demands from the society.

Conclusion. The triple helix synergy for a global health. As innovation moves outside of a single organization, lateral relationships across boundaries, rather than hierarchical bureaucratic structures, become more important. Bridges had to be built. The important question to answer is how far should the university go in taking up the mission of becoming an entrepreneurial entity in addition to its primary task of higher education and academic research, and how large the scales for political intervention should be at the university. We are witnessing a new situation in which the development of global health-related products is becoming also a political act. Anticipating the consequence of a chaotic situation in global health cannot be delayed because we are close to a chaotic situation.

Until recently, the ethical considerations of vaccine production had focused on issues related to security, efficacy and durability costs, benefits, risk assessment and the selection of appropriate experimental subject information after pertinent consent. In the fissure, social benefits and the international state of health should also play an important role in designing which type of far-ending processes are we going to carry out at the academy or the institutes of research. It is an

imperative of justice to involve scientists, politicians and industry in the task. Otherwise, nothing is going to be achieved, in my opinion.

Currently, the possibility of identifying molecules involved in the modulation of the immune system. For example, on the notes conducting the disease phenotypes is more realistic than only thirty years ago. Because of that, the scientific community should responsibly be involved in the task of the global health care, not just in his work or her work at the academy.

Academy has become a social institution and, as such, has the responsibility of contributing to the wellbeing of the society that finances it. The triple helix model as proposed by Etzkowitz is a spiral model of innovation at the international level that captures multiple reciprocal communications at different points in the process of knowledge capitalization. A new institutional configuration is therefore emerging and absolutely needed. In this scenario, all three parts of the helix will need to reach a compromise and conciliation with good will. However, we must remember that industry stands to gain the possibility of bringing to market molecular compounds or pharmaceutical products, which would otherwise be shelved. Academy, in addition to give a hand to self-financing, will find a way to translate its ideas more efficiently to the industry, which is not happening now.

It is interesting to see how big Pharma is closing in many places around the world, closing down some of their most relevant research areas and institutes. Would it be easier for them to collaborate with the academy? Public bodies, whether foundations or academia and industry, may find solutions to some of the present and future global health challenges. In summary, all three branches, academy, industry and government as regulators will gain by improving the public image and recognition. New ways of thinking are now required to profoundly affect health-care problems. It seems that an interconnected model of approaching health between academy, industry and government, is an absolute requirement to go further. As indicated by the use of a concept and language such as moral economy, interdependence may help to achieve the all-individual paradigm, able to resolve the problems we are talking about.

Para terminar, la reflexión que he hecho en estos momentos, es absolutamente necesaria por una sencilla razón, porque ni la academia,

ni la industria, ni los gobiernos tienen la financiación suficiente y el personal calificado para llevar a cabo este tipo de dificultades que nos presenta la salud mundial a este nivel.

d. Florencia Luna

Reproductive Rights; still a Pending Issue in Latin America

Latinoamérica es una región con grandes posibilidades. Se trata de un territorio con abundantes riquezas. No obstante, todavía existe una búsqueda de la justicia. Se piensa que la salud es un bien social y prevalece cierto idealismo en la forma de concebir la realidad. Lamentablemente esto no es lo único. También conviven con estas posibilidades e ideales un lado oscuro, serios problemas, mucha corrupción, autoritarismo, discriminación y fuertes desigualdades.

Una de ellas, frecuentemente soslayada y minimizada, es la condición de la mujer y el difícil respeto de sus derechos sexuales y reproductivos.

En términos globales, según la Organización Mundial de la Salud: "Cada año aproximadamente 47 mil mujeres mueren debido a complicaciones del aborto inseguro y se calcula que 5 millones de mujeres padecen discapacidades temporales o permanentes, e incluso infertilidad. Donde hay pocas restricciones para acceder al aborto sin riesgos, las muertes y las enfermedades se reducen drásticamente. Casi cada una de estas muertes y discapacidades podría haberse evitado a través de la educación sexual, la planificación familiar y el acceso al aborto inducido en forma legal y sin riesgos y a la atención de las complicaciones del aborto. En los países en los que el aborto inducido legal está sumamente restringido, o no está disponible, un aborto sin riegos se ha vuelto el privilegio de los ricos; mientras que las mujeres de escasos recursos no tiene otra opción que acudir a proveedores inseguros que les provocan la muerte y morbilidades."

La OMS también explicita que el 99% de la mortalidad materna ocurre en países en desarrollo. Implica la muerte de mujeres jóvenes, generalmente sanas y constituye un índice de inequidad. Por ejemplo,

frente a las once muertes maternas por 100 mil nacidos vivos en Canadá, Latinoamérica alcanza el 72 por 100 mil nacidos vivos.

Si bien en Latinoamérica se comparte una herencia cultural y religiosa muy fuerte, existen diferencias entre nuestros países. Para no generalizar, ni banalizar mi planteo, me centraré en el caso de la Argentina para finalizar trazando algunos paralelismos con la región.

Argumentaré que en la Argentina existe un notable doble estándar en relación a las mujeres y sus derechos sexuales y reproductivos, y que hay una discriminación muy fuerte especialmente hacia las mujeres pobres, las cuales son postergadas, silenciadas y olvidadas.

Algunos datos empíricos ilustran claramente esta situación. Respecto de la muerte materna, la Argentina se encuentra en una meseta, no ha habido una gran variación en los últimos años, lo cual ya de por sí resulta preocupante. Recuérdese que se trata de un país con un sistema de salud universal y público con más de un 99% de partos atendidos en contextos institucionales. Sin embargo, todavía más preocupantes y significativos resultan las diferencias internas que presenta.

La ciudad de Buenos Aires tiene trece muertes por 100 mil nacidos vivos; mientras que la provincia de Formosa, una provincia pobre del norte, presenta sumas exorbitantes de mortalidad materna; 123 por 100 mil; y Jujuy 115 por 100 mil.

Nótese que en tales provincias las complicaciones por abortos inseguros se mantienen, en primer lugar, como causa directa de mortalidad y que el aborto es la primer causa individual de muerte en 17 de las 24 jurisdicciones de la Argentina, y que, como también sostiene la OMS: "los riesgos asociados con el parto no se pueden eliminar completamente, sólo las muertes debidas al aborto inseguro son completamente prevenibles."

Otros datos relevantes corresponden a las cifras de embarazo adolescente. Según el estudio de población mundial de Naciones Unidas de 2013, en la Argentina, 15% del total de los nacimientos se da en niñas y adolescentes de 10 a 18 años. Esto sucede más frecuentemente en los sectores pobres, nuevamente se perciben las mismas desigualdades.

En la ciudad de Buenos Aires hay un 7%, en cambio en Formosa 24.6; y en Chaco 25 por ciento. De estas niñas y adolescentes sólo

14.8 tienen sus estudios secundarios completos; 43% no terminó el ciclo primario, y 39.4 cuenta con el secundario incompleto. Estas cifras refuerzan parámetros de desigualdad, mostrando que al menos el 82.4 no logrará una educación básica.

Así pues, éste es el panorama de fuertes desigualdades que presenta mi país, donde claramente se visualizan ciertas asignaturas pendientes respecto de nuestras mujeres, sobre todo, respecto de aquellas con menos recursos.

Por supuesto que las causas de estos fríos datos son muy variadas y es indudable que para que esto suceda existen obstáculos de todo tipo: sociales, estructurales, económicos, legales, etcétera. Obviamente debemos distinguir diferentes planos, uno empírico y otro, por ejemplo, normativo.

Es cierto que se puede argumentar que es muy difícil modificar estas profundas estructuras de fuerte base socioeconómica y que las leyes pueden ser insuficientes, sin embargo, la legislación constituye un primer paso, luego se deberán enfrentar otros desafíos.

Así, analizaré diferentes propuestas legislativas como si fueran un termómetro para ver cuáles son las prioridades en el país y hacia dónde y hacia quiénes están dirigidas las futuras políticas públicas.

A partir de aquí, entonces, querría dejar el nivel empírico para pasar al normativo y exponer ciertos cambios y propuestas legislativas, y en función de esto mi análisis evaluará cuál es la consistencia de estos planteos y quiénes son la fuente de preocupación. Pasaré revista a algunas de estas leyes.

En 2010 se sanciona la Ley 26618, que permite el matrimonio igualitario, esto es, el matrimonio entre personas del mismo sexo. Se trata del primer país en la región en legislar el tema y el décimo en el mundo. Esto posibilita la modificación sustancial de la estructura social, permitiéndose la formación de familias del mismo sexo.

Esta ley claramente evidencia una lucha en contra de la discriminación de las personas homosexuales. Pero no sólo se aprueba esta ley, también se sanciona en mayo del 2012, la Ley 26743 de identidad de género. Esta ley permite que las personas travestis, transexuales, transgénero, sean inscritos en arreglo a su identidad autopercibida en sus documentos personales. Así, pueden cambiar su nombre de pila y adecuarlo a su nueva identidad sexual.

Esta ley asimismo ordena que los tratamientos médicos de adecuación a la expresión de género, cirugías, tratamientos hormonales, integrales, etcétera, sean incluidos en el plan médico obligatorio; esto es, sean provistos gratis por el sistema público e incluidos en el privado.

En su momento, se trató de la primera ley en el mundo que conformaba las tendencias en materia, con la mayor empatía y respeto hacia estas personas, evitando patologizar la condición trans.

Nótese la brecha entre la situación recién ilustrada respecto de nuestras mujeres y estas leyes. Nótese también que para sancionar este tipo de leyes no nos encontramos frente a una sociedad consistentemente conservadora. Implica el reconocimiento de derechos y la protección de ciertas minorías, habitualmente postergadas y discriminadas en las sociedades conservadoras. La modificación de un cierto *status quo*. Así se puede señalar que la Argentina no se trata de una sociedad homogénea, donde prevalecen los valores tradicionales y no se aceptan nuevos cambios.

Frente a estas respuestas legislativas, ¿qué sucede con nuestras mujeres? Pues bien, quizás a primera vista se piense que ellas tampoco resultaron olvidadas; en 2013 se sanciona la Ley Nacional 26862, regulando las técnicas de reproducción asistida.

Esta ley, por ejemplo, establece la cobertura de estas técnicas a toda persona mayor de edad, no pone límite de edad, además de que su reglamentación establece que el sistema de salud pública deberá proveer cuatro tratamientos de baja complejidad y tres tratamientos de alta complejidad anuales.

En la mención de los tratamientos se incluye la cría o preservación de embriones. Sin embargo, no se toma partido por el estatus o formas posibles de descarto o uso de los mismos.

No abriré juicio respecto de lo atinado o no, respecto de la cantidad de tratamientos, ni respecto de que deba ser provista por el Estado.

Deseo, en cambio, centrarme en tres cuestiones: primero, que al no imponer límite de edad y abarcar a toda persona mayor, permite nuevamente la formación de familias no tradicionales, —con mujeres solas o parejas homosexuales—, lo cual nuevamente habla de políticas abiertas hacia todos y no discriminatorias.

Segundo, que se regula la provisión de estos tratamientos pero se evita tratar el estatus de los embriones, así como sus posibles usos

para implementar estas técnicas. Lo cual ante tanto progresismo resulta al menos llamativo.

Y, tercero, que aquellas a las que esta ley atiende son básicamente a las mujeres de clase media. No se considera, por ejemplo, la infertilidad secundaria a infecciones de transmisión sexual o por abortos inseguros e ilegales que afecta a las mujeres sin recursos, aquellas que no acceden a tratamiento de su salud sexual y reproductiva. Considerar a las mujeres sin recursos y sus problemas de infertilidad implicaría como mínimo realizar serias tareas de prevención, tratando las enfermedades de transmisión sexual o evitando abortos inseguros.

Todavía más preocupante es el proyecto de Código Civil, una de las herramientas fundamentales de nuestro derecho propuesta en 2012; éste muestra especial preocupación por *aggiornar* en el Derecho argentino y, por ejemplo, por legislar la filiación de los hijos de la reproducción asistida.

En esta instancia, cuando se debe explicitar el estatus legal de los embriones, el Artículo 19 de tal proyecto introduce la distinción entre embriones ex-útero y embriones in-útero. Esto permite las técnicas de reproducción asistida e investigaciones con células madres, pero continúa penalizando el aborto. Sin embargo, incluir y mantener la idea tradicional de que el embrión in-útero es una persona no permite siquiera justificar una regulación lógica de las técnicas de reproducción asistida; éstas incluyen no sólo la manipulación y descarte de embriones, sino también la posibilidad de realizar abortos selectivos. Por ejemplo, cuando la mujer queda en cinta de varios embriones a la vez, ya que no existe la política de transferir sólo uno o dos de ellos o por ciclos de inseminación artificial, donde la mujer está estimulada hormonalmente y al generar varios óvulos, por lo que queda embarazada de varios embriones.

En tales casos, se procede a abortar a alguno de estos embriones, ya implantados y en gestación, para dejar sólo uno o dos y de esta manera lograr que el embarazo llegue a término. En la jerga médica se denomina "reducción embrionaria o reducción fetal;" en la práctica es un aborto que se realiza por motivos terapéuticos, si bien fue la misma terapia la que causó estos embarazos múltiples y de alto riesgo.

En ambos casos se trata de embriones implantados y no de embriones ex-útero. Así pues, sí lo que se buscaba era permitir todas estas prácticas que, de hecho, ya ocurren en la Argentina y en toda

Latinoamérica, la solución no consiste en dicotomizar la noción de embrión, sino en dar una excepción coherente del mismo que permita brindar una respuesta a la implementación de estas técnicas y lo que estas técnicas implican.

En este sentido, los abortos selectivos y, por tanto, las prácticas que lo generan no serían aceptables, lo cual no sólo plantea inconsistencias, sino que la redacción del artículo ni siquiera permitiría la realización efectiva y segura de las técnicas de reproducción asistida, objetivo expreso de los autores de este proyecto.

También implicaría un tratamiento extrañamente desigual al permitir un diagnóstico preimplantatorio en el que se estudian y descartan embriones con enfermedades y se eligen los embriones sanos a transferir, evitando el sufrimiento a la pareja, como al futuro niño que hubiera nacido con una serie de enfermedades genéticas. Pero si la misma enfermedad se detecta con ultrasonido u otro test diagnóstico, durante el embarazo temprano, la pareja no puede realizar un aborto aun si se tratara de una grave enfermedad genética o la misma enfermedad genética detectada y evitada en el embrión ex-útero.

Tal como está redactado, el Artículo 19 resulta problemático, pero mucho más preocupante es el énfasis de esta supuesta cultura progresista por promover a rajatabla la reproducción y diferenciar entre embriones, in-útero y ex-útero.

La solución implícita parece ser la de una doble moral, legislar y defender ciertos principios, pero aceptar simultáneamente la realización de otras prácticas no permitidas y contradictorias, por ejemplo, la negación de la existencia de prácticas como los abortos selectivos, sabiendo que estos actos efectivamente se practican, aunque sigilosa y calladamente. Lamentablemente el ejercicio de una doble moral es una práctica muy extendida en nuestra sociedad, que esta propuesta no enfrenta ni detiene, sino que más bien acepta con cierta complicidad.

Esta distinción entre embriones, aun con lo perturbadora que resulta, no fue aceptada en noviembre de 2013 por la Cámara Alta. Respecto de los embriones, todo progresismo que supuestamente se defendía cayó, y más aún en 2014, cuando se planteaba un anteproyecto de código penal que no modifica la punibilidad del aborto ni siquiera para tomar en cuenta en la lógica de las causales los abortos por malformaciones o serios problemas genéticos del feto.

Ahora bien, ¿cómo pueden leerse estas leyes? ¿Cómo puede ser que, por un lado, se tome una posición trasgresora y pionera en la región mientras que, por otro lado, se ignore a la mayoría más desposeída y vulnerada? Políticas y leyes totalmente progresistas conviven con otras que sólo parecen recordar a la mujer para fomentar su rol reproductivo o para continuar condenándolas a un círculo vicioso de pobreza.

Si volvemos a Latinoamérica, podemos encontrar algunas excepciones en relación a los derechos sexuales y reproductivos; como puede ser el caso de nuestro vecino, Uruguay, que cuenta desde 2009 con una asesoría pos aborto, legisló el año pasado el aborto a libre demanda y cumple con las Metas del Milenio respecto de la mortalidad materna.

También hay algunas políticas aisladas en otros países como Cuba, y aquí en México, donde sólo en el Distrito Federal se permite el aborto en el primer periodo del embarazo.

Si bien existen estas excepciones, en general hay una prevalencia de una posición especialmente conservadora hacia las mujeres y sus derechos sexuales y reproductivos.

Chile, El Salvador y Nicaragua prohíben todo tipo de aborto, incluso cuando está en riesgo la vida de la mujer. Ahora en Chile está por cambiarlo, hay que ver si lo logra.

Guatemala, Paraguay y Venezuela lo permiten sólo cuando está en peligro la vida de la mujer. Nótese que ninguno de estos países incluye algunos casos terribles, como los provenientes de violaciones o por malformaciones o problemas genéticos.

Costa Rica prohibió la reproducción asistida para proteger a los embriones, caso que tuvo que llegar hasta la Corte Interamericana de Derechos Humanos.

Si volvemos a las cifras regionales de mortalidad materna ha habido una declinación global de 1990 a 2013, pero Latinoamérica y el Caribe es la región en la que hubo la menor declinación, aunque con diferencias, prevalece cierta falta de atención a los derechos sexuales y reproductivos.

Si bien circunscribí mi análisis al caso de la Argentina por sus flagrantes contradicciones, creo que no soy audaz al señalar que en muchos países de la región comparten una actitud de intencional olvido de los derechos sexuales y reproductivos de las mujeres más pobres.

Indudablemente, aún con sus matices, ésta todavía es una asignatura pendiente en Latinoamérica. ◗

3.9 Session 8

Chair: Angus Dawson
John Harris: *Mind Reading*
Carlos María Romeo Casabona: *New Challenges for Genetic Information Management in Research and Clinics*
Gilbert Hottois: *Is Transhumanism a Humanism?*
Nicholas Agar: *Moral Insurance for Utilitarians*

a. Introduction

Professor Harris explores the thesis that we have already developed means of extending our minds quite apart from the sort of transhumanist, perhaps even science fiction, scenarios involving genetic engineering or the implantation of memory chips. Rather, the tools we have created and used for millennia have already extended our minds. Writing enable us to communicate not only across distances but also over time, and across our extended minds can already be said to be composed of the vast written wealth of knowledge we both produce and consume. We are intricately bound to the words we communicate, and reveal things about ourselves that any student of any famous author can readily grasp. Modern technology has made the nature of our extended mind substantially different. Namely, the Internet allows for our extended selves to become known in ways few could have predicted, and purposes to which that knowledge can be put to multiply.

Social networks make our selves much more readily available to a wider range of potential subjects than ever before. As with many of the technologies discussed above, we are subjects now of scientific research which we may or may not be aware of at any one time, and over which we likely have not given consent. We can be known with significant detail, even perhaps more than we are capable of knowing. Examples of this phenomenon include the fact that national department store chains use algorithms to scan our shopping habits, create databases based upon our buying habits, to target direct advertising

to us of products the algorithms may anticipate we need, even before we know we need them. One prominent example involved a direct mail advertising pregnancy products to a girl who was in fact pregnant but who had not yet informed anyone. That girl also happened to be a minor still living with her parents. What trails do our online social lives leave about us, and to what degree might we reveal significant details through our communications and actions that violate notions of privacy we once held dear?

Our written, constructed selves notwithstanding, ourselves in our bodies are changing rapidly as well. We are all already transhumans to some degree, having modified our bodies and their environments beyond some "natural" form. Conflicting with bio-conservative notions of "nature," human nature has been malleable for some time. Eyeglasses and other similar artifacts have saved us from nature's infirmities, as has the entire field of modern medicine, witnessed in our artificially inflated lifespans. Professor Hottois explores whether transhumanism is a humanism. Humanism springs from the Renaissance effort by scholars to revive the buried knowledge of the ancients, to find among the sequestered writings of ancient Greek philosophers, often hidden in libraries kept under sectarian wraps, gems of wisdom that had become heretical, or merely problematic to the established order. Transhumanism seeks to defend the viewpoint that human nature is morally malleable to nearly any degree. It is essentially the optimistic view that there is no such thing as human nature except for what we make of it. The already prevalent techno-social creature we have created in ourselves is not somehow sacrosanct and can be remade in the image of whatever we choose both socially and individually. It embraces our ability to recreate ourselves, to adapt not only to our environment but to mold ourselves in new forms. Lifespans need not be fixed by nature any more than our failing eyesight must be. If we are free to change ourselves, then liberty is finally possible metaphysically. The caution we exercise must be rational. We are still to be guided by reason and reason imposes some limits, but transhumanism, it is argued, is essentially humanistic, revealing to us that the wisdom of nature need not be kept from us. With its tools we can better ourselves and need not conform to the rigid authority of nature any more than scholars ought to conform to scholasticism.

Transhumanism adopts the scientific viewpoint and establishes its moral adoption to the human body, revealing that the lines that previously separated us from "nature" are themselves suspect, and that both our technology and ourselves are properly, morally, subjects of our own devise. We may use ourselves as means to our own ends. Professor Agar looks at this utilitarian adage with some caution, and supposes that utilitarianism must always come with some "insurance." We cannot successfully our morally adopt the purely utilitarian viewpoint without drawing some lines, and insuring ourselves against its potentials. Utilitarians, which founds moral decision-making on the principle of decreasing suffering while increasing happiness, runs a risk of overconfidence. It appears in many respects to be a well-founded, scientific approach to the age-old problem of morality: namely, is there a non-metaphysical, objective basis by which we can assert "the good?" Utilitarianism succeeds at this where other theories seem to fail. Yet taken to its logical conclusions, it often results in decisions that accommodate its precepts, but yet seem immoral, such as the sacrifice of one for the many, etcetera. This is why a stance of humility is necessary. Utilitarians could well be wrong. To insure themselves against this, other moral viewpoints ought to generally be considered and taken into account.

In many ways, this is what we do in bioethics. The Belmont Report draws from numerous ethical traditions, including utilitarianism. As well, deontological values are built-in and regularly employed in bioethical decision-making. We are naturally skeptical or any one approach and our ecumenicalism is our strongest virtue as an applied field.

b. John Harris
Mind Reading

I've become interested recently in mind reading. You may think this is a rather bizarre occupation for a philosopher interested in science, but I will explain. The idea, the possibility of reading the mind from the outside or indeed from the inside, introspection —and I'll come back

to introspection in a minute—, has excited humanity from the earliest time. The earliest reference I could find to mind reading is in Homer.

Recent advances in neuroscience have offered some probably remote prospects of improved access to the mind. There is a different branch of technology, which looks as though it is going to be much more effective, as an agent of mind reading. Soul searching is not identical with mind reading. Nor is mind reading identical with, even if it were possible to achieve such a thing, a complete description of brain activity. An analogue here may be the relationship between genetics and epigenetics. Many neuroscientists, and indeed philosophers of neuroscience, seem stuck in an era equivalent to genetic essentialism, and oblivious to the era of epigenetics and its cerebral equivalent. My suggestion is that motives, desires, intentions, attitudes and both external and first person access to these stand to a map of the brain or a description of brain activity, as understanding the behavior of a creature or an organism stands to a map of its genome. We know from contemporary epigenetics that the behavior of genes, gene expressions, is influenced by the coding of the genes but also by environmental factors as well as, for example, being modulated by patterns of inhibits promoters, other than DNA, that are set up within the cell and are effectively self-perpetuating.

Wittgenstein famously remarked, in connection with establishing the reference of a remark of a piece of speech, establishing what object or what incident was being referred to in a sentence in a normal language; he said, "if God had looked into our minds, he wouldn't have been able to see there of whom we were speaking." Why is that? Because reference is given by context, not by brain activity. In the case of ethics, for example, and indeed, I'll give you one moral instance, the answer to the question, "Is this act murder?" or "Is this act rape?" is not to be found in states of the brain. Not least, because in the case of rape, the consent or otherwise of the other party is not to be found in the brain state of the putative rapist.

Mind reading and the relationship between the face, particularly the eyes, and the contents of the mind and indeed the soul —if you prefer to use that term— has been and remains a fascination for human kind. This preoccupation reflects an interesting fact about ourselves. We want to read the minds of other people. We want to read our own

minds. We want this so that we can understand what kind of person the bearer of the mind is, who we have to deal with, how they are likely to behave, what they want, what they're likely to do, what they have done. We need to know these things about ourselves quite as much as about others. What manner of man am I? What sort of woman are you? Mind reading, if it can be done, would be a powerful cognitive enhancer and like all knowledge, a significant source of power.

The image of the eyes, even slightly shrouded by specs, or the face as windows into the mind or the soul, often plays a seminal role in the imagery used to discuss the project of mind reading. Perhaps the earliest references to the eyes as windows on the soul come from Cicero, in the last days of the Roman Republic, who, in the following passage, is expanding on the nature of oratory, i.e. formal speech making. This is what he says, "the countenance itself is entirely dominated by the eyes; for delivery, oratory is wholly the concern of the feelings and these are mirrored by the face and expressed by the eyes."

Let's start a little voyage into mind reading with a few reflections of perhaps the greatest of all neuroscientists. I refer, of course, to William Shakespeare. We should not forget that one important dimension of mind reading involves reading the mind from the inside, introspection, but this isn't more reliable than any other forms of mind reading, because of the tendency we humans have for self-justification and for self-deception. Hamlet, confronting his mother, Queen Gertrude, with the infamy of the murder of his father and of what Hamlet regards as her incest with her new husband, her father's brother, elicits this famous response, from Gertrude, "Oh, Hamlet, speak no more. / Thou turn'st my eyes into my very soul, / And there I see such black and grained spots / As will not leave their tinct." In *Macbeth*, we find Duncan lamenting his inability to detect treason in one of his courtiers, "There is no art," he says, "There's no / art to find the mind's construction in the face." In *A Midsummer Night's Dream*, Helena insists, "Love looks not with the eyes, but with the mind / And therefore is winged Cupid blind." Helena is saying that love is not interested in superficialities like beauty, which is only skin deep, but in what lies behind. Love springs from imagined understanding, often leavened with a strong yeast of hope or optimism about the nature of what lies beneath the surface, beyond the physical gaze. She also

insists that only the mind can deliver the required understanding of what others are like.

But it is in the great play *Richard III* that Shakespeare comes nearest to my present preoccupations. Richard, newly crowned but insecure, wants another English nobleman Buckingham's approval of the murder of the little princes in the Tower who are actually the legitimate heirs to the crown that he, at that time, is wearing. He says, "Ah, Buckingham, now do I play the touch indeed, / To try if thou be current gold. / Young Edward lives; think now what I would speak." That is to say, "read my mind." He doesn't want to spell out that he wants the princes murdered, but he hopes his courtiers, like all good courtiers, will anticipate his desires and just do it. But Buckingham is a bit obtuse and later in another remark to Buckingham he says, "I wish the bastards dead, / And would have it suddenly performed."

It's probably correct that we are a long way from a neuro-scientific breakthrough in mind reading. However, recent developments in neuroscience and in particular in brain imaging have created expectations that, for example, criminal intent might be detectable in brain states. If this were really possible, which I personally doubt, then these might be used as evidence justifying restrained or detention prior to any offence being committed.

I served on an interesting working party of the United Kingdom Premier Academy of Science, the Royal Society. It was a project that delivered four reports and the project was called "Brain Waves." One of those reports was on the neuro-scientific impact on the criminal law, and we concluded in those reports that it wasn't very likely that neuroscience for quite a long time would be of service to the criminal law.

Shakespeare, primarily occupied with mind reading, was somewhat enigmatic himself, perhaps because of the universality of these themes. The English poet William Wordsworth, in a famous sonnet, suggests that Shakespeare's sonnets are the key to understand the mind of Shakespeare. He said this very appropriately in a poem called "The Sonnet," "Scorn not the Sonnet; Critic, you have frowned, / Mindless of its just honours; with this key / Shakespeare unlocked his heart."

Here we've reached the nub of the argument. It is in our writings and our interest in the writings and recorded thoughts and actions of others that our minds can be read and sometimes, misread. I want to

suggest to you that it is actually the Internet, the cloud, that is, for the foreseeable future, likely to be the most effective source of mind reading available to us, and a very effective source of mind reading, indeed.

In short, we don't need neuroscience. We already have a massive capacity for mind reading from which there is no effective defense, and here I'm speaking of those aspects of our minds, my mind and yours, that have been digitalized, that have gone into the cloud to be retrieved by anybody capable of accessing them from there. There is no defense: anything that has ever been on a computer can be hacked. If we think about what data most of us have consigned to the cloud, the list can be alarming. Just think about it. Most of us now write on digitizing kit: computers, tablets, and phones. Most of us write and receive emails, tweets and so on. Many have a web presence, a *Facebook* page, or a *Twitter* account. Moreover, the cloud contains a record of all the websites that we have ever visited, of things we have ordered online. Many of us fill in our taxes returns online, pay fines for traffic offenses online, visit online medical services; we look up medical conditions online, order drugs and services online. The whole pattern of our lives is in the clouds and competent people can always retrieve it from there.

I want to end with one telling example, a very recent example that is the example that set me thinking along these lines. It was a new story, which broke in the British Press on the 21st of March of this year, not very long ago. The BBC reported that, "a woman who threw acid on the face of a friend while wearing a veil as a disguise has been jailed for 12 years." The conviction of this woman, Mary Konye, for the assault on her friend and this guy quotes, "Naomi only was widely reported — the victim of this terrible attack who was scarred for life, had been disbelieved by the police because they examined her laptop hard drive and found that she had looked at plastic surgery websites," and indeed websites that describe of another young woman, Katie Piper —quite a celebrity in the United Kingdom—, who in 2008 was widely reported in the presses, was raped by a man she met online and then he arranged for someone else to throw acid in her face. They thought, because Naomi only had consulted these sites that she was self-harming to get attention and they dropped the investigation. Very recently, the investigation was revived and the perpetrator was prosecuted. The

police in this case were guilty of an error of inference, one of the most common errors to which all humankind is subject.

Moreover, the cloud simply contains data, often without context. However, it's there and if you really want to know about others, that's where you should look. There you can see the contents of their diaries, if they are electronic, you can see what they bought, you can see what they've looked at; you can make speculation, quite accurate speculation, about the sort of gaze that was being directed at what they looked at online. I don't think this —I think of it as a danger— has been adequately thought about in bioethical circles. People rather concentrate on neuroscience and what it might do with deep brain stimulation and brain scanning and stuff like this. That's not where our secrets are. They are in the cloud, and as the chairman of Google, Eric Schmidt, once aptly said, "The cloud has no delete button. Once our thoughts, our digitized data is in the cloud, it is available for ever as far as anybody knows." It can't be deleted.

There was a recent decision in the European court that allowed for privacy stuff that had been put on the web to be deleted by Google, but all that does is take it of particular websites. It doesn't remove it from the cloud altogether. There, there is this radical new piece of legislation, and it won't protect you. This is my final message to you: if you want to protect yourselves from others knowing a great deal about you, there is one recourse that you have and it's quite effective, but not totally effective, and that is to be very boring. If you are not of interest to the newspapers, they won't go searching for your data. Unfortunately, it is not possible, despite one's very best endeavors, always to be sufficiently boring not to interest others.

c. Carlos María Romeo Casabona
New Challenges for Genetic Information Management in Research and Clinics

Primero quiero dar las gracias a los organizadores por haberme invitado, en especial y directamente al doctor Manuel H Ruiz de Chávez, con el que comparto la oportunidad de ser miembros del Comité de Bioética

del Consejo de Europa, allá en Estrasburgo, donde también podemos discutir estos temas de bioética con los países de toda Europa.

Pero me encuentro con un dilema de cómo convino la perspectiva científica con la jurídica y de la propia organización del Congreso. Y ustedes se estarán preguntando cómo haré una síntesis de ciencia, derecho, etcétera. La verdad que el problema es mucho más sencillo, pero al mismo tiempo más complicado.

El tema de mi intervención es el principio de autonomía de la investigación en el genoma humano, sobre todo, desde la autonomía, que se deriva hacia el consentimiento. Pero lo que querría es presentar una evolución de cuáles son los puntos que han despertado en cada momento y siguen despertando interés en relación con este tipo de investigación. Y cuáles son las puertas que se están abriendo y los nuevos problemas que se plantean. Para muchos estos temas son absolutamente conocidos, pero de vez en cuando viene bien hacer una especie de repaso, un *update,* de cómo está la situación.

El interés de la investigación en determinados sectores de la biomedicina se ha debido, en gran parte, al constante desarrollo, como sabemos muy bien, de la biología molecular, al mejor conocimiento del genoma humano y otras derivaciones, la genómica, la proteómica, etcétera, así como de la utilización de un conjunto de técnicas innovadoras que permiten o permitirán la intervención en la materia viva a nivel molecular.

Hoy se están desarrollando diversas formas de concebir y de practicar la medicina clínica, lo que comportará cambios estructurales, profundos, en la actividad asistencial, como en algunos casos ocurrió hace años.

Se pueden destacar varias de ellas que toman como punto de partida ese conocimiento mejor y más detallado del genoma humano, de las funciones de los genes que lo componen y de las repercusiones para la salud de ser portador de genes deletéreos o, diríamos también, defectuosos.

Esto ha permitido mejores formas de captar los aspectos jurídicos más relevantes y, en ocasiones, más problemáticos relacionadas con las investigaciones sobre el genoma humano.

Pedíamos recordar simplemente, a título orientativo, la llamada medicina predictiva, y preventiva, la medicina personalizada o

individualizada, y la medicina regenerativa, aunque ésta se mueve en una mezcla de la información genética y de las posibilidades que, a distinto modo, puede ofrecer la ingeniería genética en el sentido más amplio.

En cuanto a los puntos que han despertado interés, algunos ya están más sedimentados, otros son conocidos pero todavía no están muy elaborados; sobre todo en algunos países, están abriéndose camino. Cuando se está sondeando, generando expectativas y, al mismo tiempo, planteando problemas, el tiempo nos acabará diciendo si realmente hay expectativas, y si realmente hay problemas, tal y como se han concedido ahora, o el futuro mismo los podrá resolver.

Por ejemplo, los datos genéticos con fines de investigación —algo que empuja con gran fuerza desde la década pasada—, es la utilización de material biológico humano; es decir, muestras biológicas con fines de investigación, lo que ha generado un discurso ético y un marco jurídico en algunos países y ha derivado hacia los llamados biobancos, precisamente con fines de investigación, que es un tema muy importante, un gran eje y un gran resorte para apoyar la investigación.

Como en muchas ocasiones carecemos de referentes éticos compartidos, sobre todo fuera del ámbito europeo, por consiguiente no se han podido reflejar en legislaciones. Un ejemplo de las referencias normativas claras, podrán gustar más o menos, pero claras y detalladas, es, en España, la Ley de Investigación Biomédica de 2007 y un Real Decreto, precisamente, en relación con las materias de pruebas, de muestras biológicas y de los biobancos.

Algo de lo que se está hablando hace ya cierto tiempo y que todavía no sabemos hacía dónde podrá ir, desde el análisis y su trascendencia ética, —y si debería y de qué forma intervenir el Derecho—, es la secuenciación completa del genoma humano.

Un asunto también muy importante que la expansión de la investigación o del ámbito de la genética, y en general de la biología molecular en general, que está forzando otras vías de investigación, es la colaboración de grandes equipos para compartir información genética y poner a disposición de todo ese conjunto de investigadores de distintos países dicha información y, en ocasiones, hasta las muestras biológicas.

¿Qué marco jurídico puede alcanzarse en este último ámbito, cuando estamos hablando de la necesidad?, o por lo menos ¿qué es lo

que primero se le ocurriría a un jurista encontrar que pueda proyectarse a las relaciones de intercambio de material genético y de datos genéticos entre los investigadores que provienen de distintos países, con culturas jurídicas diferentes?

Por mencionar algunos de estos asuntos, en primer lugar, hay que señalar que respecto a los datos genéticos es ya bien conocida su importancia para utilizarlos con fines asistenciales.

Pero también la posibilidad de destinarlos a la investigación, pese a que estos materiales biológicos y los análisis correspondientes que dan lugar a información genética haya sido procesados, obtenidos y supervisados directamente para investigación, bien sea que se aproveche haber obtenido este tipo de análisis o incluso muestras que quedan todavía almacenadas y que de ese fin inicial asistencial, se quieran destinar a la investigación. Esto plantea problemas muy interesantes y que parece se van sedimentando.

Se considera, en todo caso, que estos procedimientos, técnicas o instrumentos de investigación deben ser objeto de regulación jurídica. Por tanto, tenemos un ámbito en el que se piensa que no debe quedar en el marco de la esfera de la reflexión ética y, así, de las respuestas meramente éticas, sino que el derecho —en la medida en que se pueden ver involucrados derechos fundamentales, libertad de las personas y otro tipo de derechos o intereses de los individuos y de las colectividades— requiere establecer a través de sus instrumentos los marcos regulativos adecuados.

En segundo lugar, en caso de desinterés por proteger o de que el derecho establezca reglas jurídicas en relación con los datos genéticos, sabemos de la importancia que tienen los datos genéticos, sobre todo si hay formación que pueden revelar.

Se reconoce de forma unánime que los datos genéticos constituyen una variante de los datos relativos a la salud, en particular los datos que provienen del ADN codificante. Por consiguiente, han merecido de la mayoría de parte de los instrumentos jurídicos internacionales —por mencionar uno, la Declaración Internacional sobre los Datos Genéticos Humanos— una protección especial.

Reafirmamos que el dato genético es un dato relativo a la salud que presenta unas características, por lo que debe tener el mismo marco regulativo y protector, fundamentalmente protector.

Cuando decimos esto debemos tener en cuenta que, además, los datos relativos a la salud en general han merecido, tanto las legislaciones de los Estados como el de estos instrumentos jurídicos internacionales, una protección reforzada, una mayor protección jurídica, una más intensa, ¿por qué? Porque el acceso de terceras personas sin ningún tipo de control a dichos datos convierten a las personas de los que provienen, en sujetos vulnerables, frente al uso abusivo de esa información.

Esto ocurre igualmente en los datos genéticos; si se tiene en cuenta cuál es la característica diferenciadora más importante del dato genético en razón, precisamente, de su género del dato relativo a la salud, es que son predictivos. No sólo son datos sintomáticos de la salud que nos dicen cómo está nuestra salud y, por tanto, es un instrumento que se ha incorporado a la medicina clínica de los grandes centros hospitalarios. Éste nos predice lo que nos va a ocurrir o lo que nos puede ocurrir mientras el estado de la ciencia no evolucione.

Todos sabemos que podemos hablar dentro de una propensión, una proclividad de desarrollo de una enfermedad —como es el cáncer— así está establecido.

Otro ejemplo de esa especie de determinismo, una frase o expresión que no me gusta en absoluto, relativo a datos de la salud son las enfermedades monogénicas dominantes.

Por tanto, si estamos utilizando este tipo de información, habrá que velar la investigación científica, habrá también que utilizar procedimientos. Afortunadamente, tenemos algunos instrumentos internaciones, algunas legislaciones nacionales, como la española, en las que esos datos se transfieren a otros investigadores con las garantías suficientes. ¿Con qué garantías? Aquéllas que precisamente están encaminadas, sobre todo, a la protección de la persona de la que provienen esos datos.

Como es sabido, en la evolución científica y la práctica de la investigación se han encontrado soluciones dentro del marco general de la legislación sobre protección de datos y si alguien quiere investigar y quiere acceder a la información, incluso una muestra biológica, habrá que darle esa información de forma anónima; es decir, que no se sepa a quién pertenece. Lo cual significa que no sería reversible, no sería posible reidentificar, en términos generales, a esa persona.

Por consiguiente, ésta sería la norma; en ocasiones nos encontramos con excepciones en que el investigador dice: "no, yo necesito saber a quién pertenece esta información porque quiero hacer un estudio retrospectivo y entonces tengo que saber cómo ha ido evolucionando el paciente". En estos casos sí está justificado. Además, un órgano independiente, como son los comités de ética de la investigación, tendrá que supervisar que se establezcan garantías suficientes para que quienes se vean implicados ejerzan el deber de confidencialidad y para que no se corran riesgos excesivos de que la información pueda llegar a terceras personas.

Otra cuestión importante es que ha ido bajando de forma constante y considerablemente el coste de la secuenciación completa del genoma humano de individuos. Hace unos años se decía que dicho costo podía estar cerca de los 160 mil dólares y ahora se está hablando pues de unos mil dólares; hay una diferencia enorme, lo cual significa que conocer todo el genoma de un individuo va a estar al alcance relativamente de las personas, de los centros sanitarios y también, claro está, en el ámbito de la investigación.

No voy a entrar en la cuestión de la utilidad que pueda tener la secuenciación completa del genoma humano. Realmente es muy prometedora. Sin embargo, no deja de plantear problemas nuevos. ¿Qué ocurre? No sabemos. Tenemos experiencia a lo largo de tantos años en los que la bioética se ha aproximado a los dilemas éticos y a las respuestas jurídicas que plantean. Esta moderna investigación científica desde hace años, esas prácticas asistenciales en constante perfeccionamiento y evolución —que lo que en un momento aparece como un problema al cabo de poco tiempo— diluyen ese problema por sí mismo y, por tanto, nada tenemos que hacer.

Una medida prudente, — que, además, aconsejamos especialmente los juristas—, es que antes de tomar grandes decisiones que puedan afectar a las prácticas diarias, tanto en la parte asistencial como en la investigación, se actúe con prudencia; es decir, antes de tomar una decisión que pueda superar una constricción, una restricción, una limitación de prácticas de derechos de investigadores de pacientes, en fin, de los centros de investigación y de los centros asistenciales, vamos a ver realmente qué es lo que está pasando, o al menos qué, prudentemente, y razonablemente puede ocurrir.

Entonces, los problemas que plantean actualmente y de forma general los análisis genéticos en que se hacen secuenciaciones y análisis muy concretos se multiplican, no voy a decir al infinito, pero casi.

Por consiguiente, hay que tener en cuenta qué puede ocurrir con los hallazgos de posibles enfermedades en una persona a la que se le ha hecho la secuenciación completa del genoma humano.

Descubrir que una persona es portador de algún gen, de varias secuencias, de hasta cientos de secuencias, ¿tiene sentido informar al paciente si no se puede hacer nada con ello, sin un tratamiento? Es generarle una vida constreñida a aquello que le puede pasar. Todo esto hay que racionalizarlo.

Y, por consiguiente, si se va a manejar una inmensa cantidad de información, hay que gestionarla con exquisito cuidado y exquisito control, de tal manera que ningún tercero pueda acceder, porque acaso realmente desde una perspectiva puramente genética, estaremos desnudos.

Ya lo dije antes: no soy determinista. No creo que toda nuestra realidad, esté en nuestros genes; está en nuestro yo, en nuestra personalidad, que es el fruto, el resultado de muchas interacciones, desde que estamos en el vientre materno hasta que vamos creciendo.

Creo que eso va a requerir de los conceptos que hablábamos, de los criterios y principios éticos que daremos como aceptados, y que habrá que readaptar a esta posibilidad de la secuenciación completa del genoma humano, que yo no veo que a corto plazo vaya a ser muy importante tal vez para fines de investigación.

Ya les he dicho que hubo temas interesantes, la investigación trasnacional, el intercambio internacional de datos genéticos para grandes equipos, y cuando hablo de grandes equipos, en el sentido de que hay muchos países implicados, requiere otro tipo de medidas, frente a las cuales el derecho está más desasistido, porque no hay nada obligatorio regulado a nivel internacional. Parece que sería, incluso, difícil que los Estados estuvieran en condiciones de tomar interés por esto y entonces se trata de ver cómo se armonizan y se coordinan las legislaciones nacionales, para que ese intercambio de datos o, en su caso, de muestras, sea de forma provechosa para la investigación, pero al mismo tiempo respetando los derechos de las personas implicadas.

d. Gilbert Hottois

Is Transhumanism a Humanism?

Transhumanism has gained public visibility recently after several official reports from the US and the European Union. The best known is the US report *Converging Technologies for improving human performance. Nanotechnology, Biotechnology, Information Technology and Cognitive Science* (NSF and DOC, 2002). It clearly promotes a RAND D policy regarding human enhancement and it has provoked reactions from the EU.

In 2004, the report *Convergent Technologies for the European Knowledge Society* emphasized the need for increasing knowledge in these matters, as well as improving natural and artificial environments. Material technologies should apply to material environments; the human body and brain do not belong to these categories. The report opposes the transhumanist agenda, while referring to the warning emitted by the US about the transhumanist ambitions to "Improve human performance" (*ibidem*. p 7).

In 2009, a Report for the European Parliament titled *Human Enhancement* gave numerous examples from the most trivial to the most speculative: amphetamines and such, Viagra, doping in sport, gene therapy, eugenics, anti-aging treatments, human-machine hybrids, brain prostheses, new non-human senses, and cyborgs, among others.

The Report describes at length the transhumanist trend strongly supporting enhancement and concludes that transhumanism must be taken seriously: "Attempts to ignore or ridicule the transhumanists as an insignificant techno-cult [...] have turned out to be futile endeavours. Although many of the transhumanist visions have a smack of science fiction [...], they have managed to gain considerable ground in the ethicopolitical debate on human enhancement as well as a rather widespread attention in diverse academic fields and in the media" (*ibidem*, p. 113).

"Transhumanism" refers to a nebula of ideas where serious arguments are neighboring with fantasy. It is not difficult to select texts and statements to discredit it. My approach is constructive, for I think transhumanism is worth attention. It provides the possibility to articulate in a coherent way a wide range of ideas and issues:

anthropological, epistemological, ethical, political and even ontological, scattered over bioethical debates. This was already undertaken in the late 1990s, with the creation of the World Transhumanist Association (WTA) by Nick Bostrom and David Pearce (1998). Texts were produced as part of this association, renamed Humanity in 2008. However, this does not exhaust the relevant references for a philosophical development of transhumanism. Interesting references are part of bioethics literature at large with several authors who do not call themselves "transhumanists," while sharing several ideas and values.

In answering the question, "is transhumanism a humanism?" I will try to illustrate some aspects of the philosophically unifying potential of transhumanist critical thinking.

First, let us recall that transhumanism situates itself in the wake of the Enlightenment, especially Nicholas de Condorcet. But the historical reference that militates most in favor of a humanistic vision of transhumanism is Julian Huxley, biologist, brother of Aldous, and first Director General of UNESCO. In 1957, Huxley coins "transhumanism" as a synonym for what he had called, long before, "evolutionary humanism." His project was to build an ideology capable of integrating science and technology, and victoriously able to stand comparison with traditional religions; the biological evolution that has produced the human species is its central hypothesis. But the central concern is the future of the human species in the perspective of the coming evolution that man must now take charge of.

Huxley rejects reductionist materialism and spiritualism and attaches great importance to the activities and products of the mind. But these mental productions –culture, ethics, art, science, etcetera– come from man who is part of nature himself. They refer in no way to a supernatural realm nor a spiritual or ideal reality independent of the human brain. They should therefore also gradually become the subject of empirical and experimental investigation. Humanism according to Huxley must be naturalistic —opposed to any supernaturalism; monistic —opposed to any dualism; and evolutionary —opposed to statism. Humanism, naturalism, monism, and evolutionism thus characterize "transhumanism" and clarify its introduction in the last lines of the text *Transhumanism* (in *New Bottles for New Wine*, 1957). The following passage is often quoted: "The human species can, if it wishes, transcend

itself [...] We need a name for this new belief. Perhaps *transhumanism* will serve: man remaining man, but transcending himself, by realizing new possibilities of and for his human nature."

The vast majority of transhumanists are agnostics or atheists, secular and freethinkers, their values and declared intentions are close to modern progressive secular humanism.

It is true that Julian Huxley introduced transhumanism as an ideology with the weight of a religion without dogma. But current transhumanism avoids most often displaying a similar ambition. It focuses more modestly around the notion of physical, cognitive, and emotional enhancement, and it advocates a method of case by case assessment of the proposed or potential improvements as happens in bioethics committees.

Transhumanism has an optimistic faith, voluntarist and rationalist, in the future, in human creativity, and responsibility. It rejects fanaticism, intolerance, superstition, and dogmatism. It distances itself from traditional and modern humanism by relativizing the exclusive value given to an individual human being as member of a biological species. It denounces human specieism: the specific human biological form is not sacred, it is not immutable, and does not have a monopoly of respect and dignity. Transhumanists prefer the notion of "person," defined by the presence of certain attributes: awareness, sensitivity, the ability to reason and to choose, etcetera. What separates man from other living beings is not absolute difference but a matter of degree: animals may share to some degree characters of a person. These observations would also apply for trans- or post-human entities, although today this is only speculation, who could share some attributes of the person. Transhumanism asserts that all sentient beings, possibly conscious, pre-human, non-human animals or post-human, are entitled to a moral status, and we should be respectful of their well-being and flourishing.

The emphasis on the concept of "person" also denounces the value judgments and discriminations associated with differences of race or ethnicity, sex, or gender. One of the criticisms addressed to modern humanism is that it has privileged the figure of the white, western, male human. Transhumanism is "post-humanist" in the sense that it dismisses these prejudices of humanism.

At the core of transhumanist values is the autonomy of the person, who is free to modify his/her body and its particular and contingent morphology. This fundamental right connects to parental autonomy, freedom of procreative choices. Transhumanism is opposed to any totalitarian politics, and disrespectful of individual and parental autonomy. The fictional worlds of Aldous Huxley and Orwell are radically anti-transhumanist.

Transhumanism is materialistic only if this means that it opposes dualism and spiritualist substantialism. But materialism does not succeed in defining the essence of matter. Matter is both mechanical and alive, substance and energy, thinking and conscious, infinitesimal and immense... Such materialism is opposed to what is often labeled, "reductionist or simplistic;" rather it is multiplying. The tools in this multiplication are the technosciences (including those I started mentioning: NBIC). This operative materialism does not seem incompatible with Huxley's monism.

Material technologies applicable to humans are quite central to transhumanism. Their importance is a major difference between transhumanism and traditional humanisms, including modern secular humanism. Humanism regards progress first or exclusively in terms of social transformations, institutional, symbolic organizational –education, ethics, law, culture, policy–, without really considering deep biophysical changes in humans. Humanism, even modern and secular, has no ambition to fundamentally change human nature and its limits. Transhumanism is characterized by a willingness to fight effectively against finitude and death. It points out that much technoscientific research is being made in the field of ageing and longevity in non-human animals and humans. Religions and philosophies have never ceased to "justify" death, as long as it was a foregone conclusion, against which there was actually nothing to do. This situation has started to change. Transhumanism encourages this evolution, while leaving each individual free to celebrate finitude or the fiction of a supernatural life after death. However, from now on, religions and philosophies justifying or advocating finitude are negative forces that encourage inaction and fatalism.

Transhumanism is humanism without *a priori* limits. The finiteness of the person is empirical, not ontological. The speculative and

narrative reference of religious and secular humanisms was History; that of transhumanism is Evolution.

The 20th century has been described as the age of collapse of the Grand Narratives that gave meaning to History. Transhumanism is able to propose a new narrative, but an open one, to be written century after century, with a rich speculative imagination and capacity for integrating technoscientific advances. A story without religious or secular eschatology, nor terminal utopia, a story whose end could not be anticipated, and which bears an endless expectation and hope.

The transhumanist Grand Narrative starts with a look back at the cosmic and biological evolution; it continues with human evolution considered from the technological angle. This chronicle of the human species, described as having always been a technical species, tells the story of mankind as a history of improvements due to techniques invented by humans: stone, language, writing, printing, agriculture, motors, industry, internet, NBIC, etcetera. The assumption on which transhumanism bases the continuation of its grand narrative is that technological developments will continue and that the full potential of technologies will be gradually realized.

But this optimistic scenario for the future is not the only possible one and its implementation is not guaranteed.

Nick Bostrom examines four possible futures:

1) *Extinction*: its probability is high due to countless natural, cosmic, and technology hazards; 99% of terrestrial species have eventually disappeared.
2) *Recurrent collapse*: one can imagine a series of catastrophic collapses of human civilization followed by restarts. But it is doubtful that this will last indefinitely; the farther away in the future, the less likely it seems.
3) *Plateau*: stopping the biological, technological and social evolution; a state of stagnation and balance maintained indefinitely. Also unlikely, especially as we move away in the future, because of all the potential causes of instability or destabilization, internal and external, of the human species (pp. 9-12);
4) *Trans/post-human evolution*: evolution with self-enhancement/transformation *ad infinitum*.

Bostrom believes that over the long term, the two most plausible assumptions are the first and last ones (p. 15).

The unity of the transhumanist Grand Narrative is formal; contents could be multiple, recalling the many ways that natural evolution has followed. Being tolerant and protecting the autonomy of persons, transhumanism projects self-evolution as involving multiple modes of development, and diversification. It does not place the future under the law of universal and unitary progress. There is some postmodernism in transhumanism, but it does not sink into the relativistic and nihilistic excesses. It saves basic modern values and respects technoscientific methodology.

The evolutionary transhumanist Grand Narrative, centered on the idea of enhancement, breaks with the exclusive dominance of the therapeutic paradigm as the assessment grid for biomedical innovations. Traditional and modern humanisms usually remain prisoners of the therapeutic paradigm and the prejudices associated with it, including the idea of an immutably given human nature.

Evolutionism is a potentially "dangerous" paradigm: it can be interpreted and applied in a simplistic, brutal, insensitive way, and lead to a world actually inhuman and barbaric.

Transhumanism carries considerable risks related to equality, justice, and solidarity in a society of performance dominated by the market. These risks are sometimes underestimated by transhumanists. This concern can be read in some European reports I mentioned as well as in some texts of the WTA.

Risks and limitations of the prospective are linked to the immense complexity of the enterprise of technological improvement of individuals, given all that can go wrong, on the short, medium or long term in the field of physical and mental health, as well as in social relations. However, the risks will not be solved by less technology or a return to the past, but through more appropriate new technologies, freely accepted applications in the sense of physical, cognitive, and moral enhancements.

Unlike humanism, transhumanism emphasizes evolution and material technologies. It compensates for the humanistic deficit about them. This rebalancing does not mean abandoning the ethical, social,

or symbolic acquisitions of humanism, such as human rights. Solidarity, inclusiveness, and justice are values to be preserved without immunizing them from technoscientific approaches, be it comparative ethology or genetics. Transhumanism calls for a better balance between the symbolic and the technique. It invites to give at least as much weight to the technical, the operating as to the symbolic, and the speculative.

Nevertheless, the transformations envisaged by transhumanists could become so radical, with unpredictable consequences, that the anticipation of the future society and humanity could become very limited and uncertain. An expression of these limits of transhumanist prospective is the "posthumanist" idea: a transformation so deep that the products of enhancement would be so removed from our human condition, that we would have little or no relationship with them. From the trans-human to the post-human the boundary is unclear and unpredictable.

If thanks to science, technology and human values, we are not totally blind and devoid of light, we should remember this light is limited.

Transhumanism does not imply a break with humanism. Of course, in order to promote enhancement and the right of individuals to freely use techniques for personal development and flourishing, you do not need neither a new grand narrative nor a renewed vision of the place of man in the cosmos. Utilitarianism, liberalism, and pragmatism will do. Transhumanism therefore speaks primarily to those who, without rejecting these more classical philosophies, consider that they are not sufficient.

Transhumanism offers something to answer to religion and metaphysics, which continue to play a huge role of legitimation, often implicit or even unconscious, in discussions and decisions for or against research proposals and innovations. Transhumanism recalls the separation of Church and State, the privatization of issues about the ultimate meaning of life, and also supports the use of technologies that question philosophical and religious values. Transhumanism also has something to say in response to nihilism, i. e. the vacuum left by the collapse or retreat of the great religions and modern ideologies. Transhumanism encourages us to confront the abyss of the human condition in the technoscientific age (see the four scenarios of Bostrom) without seeking refuge in the symbolic shelters of religions

and idealistic philosophy, or sink into nihilism or dissolve in relativism. Transhumanism rationally and deliberately promotes the self-transcendence of the human race in the ocean of space and time, full of risks, dependent and independent of its own actions and abstentions.

Is transhumanism a humanism? It may be, provided that we do not apply a restrictive definition of humanity and that we pursue the ideal of indefinite improvement with the greatest caution. Its significance is also critical: transhumanism invites us to dismiss prejudices and illusions attached to traditional and modern humanisms. Transhumanism is a humanism, religious and secular, becoming capable of integrating technoscientific revolutions past, present, and future; able also to cope with the indefinitely long time of evolution and not just the finalized temporality of History. It is a humanism capable of extending, diversifying and enriching itself indefinitely.

e. Nicholas Agar

Moral Insurance for Utilitarians

What am I going to talk about today? Basically, I'm going to talk about the dangers of being an overconfident utilitarian. There's nothing dangerous about being a utilitarian. I'm a utilitarian and I sign up to a view that sort of says, "Yeah, when I listen to the talks in this conference, I'm at my first port of call when I think: "well, how do I approach this moral problem," is to try to address it in utilitarian terms. What's the option? What's the action that causes the most happiness and the least suffering? I think, that for me, is the best moral theory. That's the one that's the most useful. But I think that like any really useful tool, it can be misused, it can be over relied upon, you can be too over confident about it.

Maybe I can sort of draw an analogy, which maybe will be offensive, but shouldn't really be. In New Zealand, and I'm sure it's a problem the world over, young male drivers tend to kill themselves in numbers that are far too great. The problem is one of overconfidence, so they think that are better drivers, and I think it has to do with the development of the young male brain —they think they are insensitive to risk; so

they take risks that they should recognize as just really, really bad and they end up dying. I guess I want to say that there's a certain kind of utilitarian who's kind of the moral philosophical equivalent of a seventeen-year-old boy driver, way too confident. You can improve a young male driver by making him less confident, you just have to tell him, "You are not a great driver, you know? Perfect, don't take these crazy risks, you won't be able to pull them off." You can make them better. I think you can make utilitarians better, morally better by making them less confident.

I'm not sort of going to stay there, but I've got something practical to contribute a tool you can use to become less confident. What if I give some examples of utilitarian overconfidence? I've got to say that, I don't know, the utilitarianism, the versions of utilitarianism they get into the newspaper tend to be expressions of overconfidence and do not explain how they can lead us into error, but I want to give a sort of tool for a sort of way of avoiding it and this is the idea of *moral insurance*. You should insure yourself against the possibility of error. I guess sort of who's a good example of an overconfident utilitarian: Peter Singer.

I guess that comes from a debate. It actually was sort of covered in a documentary of the BBC. It's actually, it was a terrible documentary because it's a real case of how a journalist can misrepresent a philosophical debate. It's kind of a debate; it's a 2009 BBC documentary. Actually, the BBC ended up apologizing about it, but it basically was addressing the very important and big issue about medical experiments on animals. Is it morally permissible to inflict painful, a lot of suffering on animals in order to get better treatments for human diseases? There was this person, Mel Broughton, who was going to be kind of unflatteringly portrayed. He was the advocate of the animals and he was frequently presented shouting into a megaphone, and on the other side was the advocate of animal testing, a professor at Oxford called Tipu Aziz, who in contrast was often portrayed, sort of, empathizing with young patients with neurological disorders. It purported to be a balanced presentation of this debate: here's one view, here's the other view, one view... But it was all about whether Oxford University should build a lab in which these experiments would be performed. Therefore, the protestors were trying to stop Oxford from building that.

I guess that was kind of ambitious in a way, because it's sort of saying, "Well, it's one thing to have these people arguing with each other. Let's resolve this. And how do you resolve this? Well, let's bring in the spiritual leader of utilitarianism, of animal welfare, of animal liberation. This is the guy that Mel Broughton worships. Let's find out what he says." He was asked this question, which was basically sort of a question posed by Tipu Aziz. He heard the question and his answer was Yes." The documentary treated this as a sort of scandal; you get the Pope, and you ask the Pope, "You don't really believe that this God person, this God being really exists, do you?" and the Pope says, "No." And so this was treated as "This is it!, this is it! The father of animal liberation says animal testing is OK. So, where's this idiot? He has just got to get lost." The documentary concluded, "This is a settled moral issue, animal testing is fine."

It was pretty fraudulent in a way, and I guess it made Peter Singer pretty angry, because it's not very surprising that his answer was that. If you ask a utilitarian a question, a similar kind of question about pedophilia, "Is it ever right? Could it ever be right to perpetrate a pedophilic act?" Then the utilitarian would say, "Yes, I can easily imagine circumstances in which it would be right. I mean, if perpetrating a pedophilic act, one act, is the only way to prevent a 100 pedophilic acts, when these are terrible circumstances, then yes, it would be right to do it." So, it's not surprising that Peter Singer is a utilitarian. His answer was kind of, "Duh! I mean I'm a utilitarian, if it really does reduce suffering, then I'm in favor of it." I guess it's sort of in the same way that if you can get Peter Singer to say, "Well, it might be possible, I can imagine that a pedophilic act might be OK," there shouldn't be a headline saying, "Peter Singer In Favour of Paedophilia," because, of course, he would say, "those circumstances don't obtain. Pedophilic acts in general cause huge amounts of suffering, so I'm opposed to them. Just because it's possible to imagine that, under some very rare circumstances, some of these acts might be good." It's kind of, absurd. This is not surprising; this isn't the analogue of the Pope saying, "Come to think of it, there is no God." This is what a utilitarian has to say, "If you can inflict a little suffering on a rhesus monkey, and that's the only way to cure this terrible disease, if you can't get it any other way, then, yes, you should do it;" but I guess he also says that almost all medical

experiments conducted on animals don't satisfy that condition, that's why he is an opponent. That's great. That is not an example of Peter Singer being overconfident. I'm fine with that. That's just an example of him being a utilitarian.

Here's where it comes to pieces. Basically, if you misquote a philosopher, if you misquote an academic —I guess—, the time-honored punishment for getting someone wrong like that is a lecture. And the great thing about being Peter Singer is that, as it is, you're famous; so usually when New Zealand papers quoted me and got me wrong, I'd say, "Well, you didn't quite get right on that," they say, "We don't care. We just wanted someone to turn up to say something slightly eccentric, and we are happy with that." But I'm not Peter Singer. He actually gets to have the last word and he basically sort of said, "Well, look, there's a sting in the tail, here's something unpleasant for Tipu Aziz. Be consistent. It could be right to inflict painful, hideous experiments on non-human animals, on rhesus monkeys, but if you say that, then you should be prepared to inflict the same experiments on human beings with a similar level of mental capacities. So, that's the price. Be consistent."

Basically, if you deny that, according to Singer —this is the famous aspect of Singer's view—, you're basically the equivalent of a racist. If you think species boundaries make a difference to the treatment that you deserve or some other being deserves, it is the same as saying, "well, look, what racial group you belong to makes a difference." Both are bad reasons. So this is the cost. And I would say that that's where Singer went and got over-confident, that's where he turned into a seventeen-year-old boy who broke into his father's tequila cabinet and took the car out. He shouldn't have said that. This is where Singer needs some moral insurance and I'm here to sell it to him.

Here's what I want to say: he's wrong about that. He should not have said those last two things. He's wrong in general about how he should respond to utilitarian claims. You can be utilitarian without responding to them as he does. I'm going to make some assumptions. These are the things I assume, I won't argue for them, but I happen to believe them. Basically, utilitarianism is the best theory of normative ethics, I actually believe that —I'm not forcing you to believe it. So, those of you who aren't utilitarians can get some *Schadenfreude* out

of this, as if utilitarians fighting each other were enjoyable as a spectator sport. Also, what I think is right; Singer is correct about what utilitarianism says. When he says that utilitarians shouldn't make a distinction between a rhesus monkey and a human being with similar mental capacities, he is right. Utilitarianism does not find a difference and we shouldn't distinguish then on utilitarian grounds.

I think utilitarians should take out insurance against the falsehood of their views. You can be very confident that your view is correct, but you should still in a way be alert whether you might be wrong; but as an actual fact, it's a weird thinking that we do all the time when we buy insurance. I'm pretty confident that my house won't burn down. If you are asking what am I going to do at the end of this conference, I'm going to try and see a bit more of Mexico City. I say I am going to fly home, I don't say, "Well, I guess if my house hasn't been destroyed, I'll fly home. Otherwise, I don't know what... All of my wealth is tied up to my house, so I guess that's a big problem for me." I'm confident. In the language of subjective probability, we sort of say, what's your subjective probability —talk about credence—, how strongly do you believe something? My belief that my house will still be there in five days' time, I'm pretty confident, I'm very confident, confident enough to assert it, OK? That's very unlikely. The house that we live in, spent the last thirty years, basically, being occupied by students from Victoria University and they didn't manage to burn it now. We have no open fires; we are not going to burn it down. My wife and kids, they are not going to burn it down. I'm confident. But I still have fire insurance. I guess it's sort of easy to understand: fires do happen, and if they do happen, that's a disaster, that's basically all my wealth gone there. That's why I have an insurance policy. It makes sense to me to have an insurance policy that's cheap enough. It's cost me a little bit, but not too much given the possibility that my house would burn down, since that outcome is very bad.

I think that utilitarians should do something similar in respect to alternatives. They should look around; they should go to meetings like this and discover that there are such creatures as non-utilitarians. They believe these other theories like maybe, Kantianism, some other version of deontology or virtue ethics... I don't believe those theories, but I guess I do think that they are reasonable. When someone sort of

says, "well, I'm a virtue ethicist," I don't just say, "You idiot!" That's the end of that conversation. I sort of understand, "OK, you've arrived at a different conclusion from me. I don't believe what you believe, but you are not an idiot, necessarily. I can see that that's a reasonable view." I guess I sort of think that basically this is the floor of overconfidence and utilitarianism; not making this concession and that it has sort of relevance for what we do.

We've got to recognize that there are other views of morality out there that are not absurd, that are reasonable. Intelligent people believe them; don't make sort of stupid claims of odd human beings alive, they are not necessarily contradictory; but we should actually make a distinction, as philosophers make far too many distinctions, but this is really the only distinction I'm going to make. We should distinguish; we should consider reasonable views that we happen to disagree with. Kantianism is a reasonable view, as well as virtue ethics; I happen to disagree with them, however I'm going to treat them differently from other alternatives that are unreasonable. If you turn up and say, "You're a Nazi, I'm not going to listen to you, sorry," that's because I think there's not a zero probability that your view is correct, but it's pretty remote; however, to come up with a version of Nazi morality that makes sense isn't obviously contradictory.

It's the moral philosophers' equivalent of flat-Earth theory. If you are a geologist, and your Head of Programme of Department tells you, "We've just hired the leading advocate of flat-Earth theory. It's a great celebration for the Department," be very depressed. That's not a reasonable alternative. And I think the same about Nazi morality, if my Head of Programme tells me, "We've just hired the world's leading Nazi moralist," then that's very bad, that's not a competent person. That's not reasonable, I guess that's got a non-0 probability of being correct; flat-Earth theory, it's got a non-0 probability of being correct, but pretty close to 0.

In terms of insurance, I do insure against fire, I don't insure against the destruction of my house by an extra-terrestrial death ray. That would be a bad thing, I wouldn't enjoy it, but I'm entitled to say, "well, look, fires happen, they are improbable, but aliens with death rays... Although possible, I'm not going to waste time." Basically, if you are

prepared to spend even a tiny fraction of a peso buying an insurance policy that protects your house against destruction by extra-terrestrial death ray, then you are in trouble, because I'm going to sell you a policy protecting your house against an escaped dinosaur from a cloning lab; you are going to be spending a lot of your time. If you have indefinite time, then great, but if you don't, then don't. Just dismiss the unreasonable alternatives. I guess my claim is that basically there are alternatives to utilitarianism that should be taken seriously and that turns out to be practically relevant.

If I'm going to be a reasonable utilitarian, an insured utilitarian, I should basically protect myself. I want to be insured. I believe these theories are true, the other theories are false, but, what happens if they are true? What are the costs? I mean, if you find that, for example, sound animal testing, Singer says, that if you are prepared to conduct a lethal medical experiment on a rhesus monkey then you should be prepared to conduct it on a human being with similar mental capacities. I don't know about virtue ethicists, and Kantians and non-utilitarians, but I imagine if you were to do that, they wouldn't just say, "That's a little bit wrong," they'd say, "that's a horrible action." When you say, "this person is profoundly mentally disabled, don't worry" —that's a terrible thing according to these reasonable alternatives.

What's the difference, I mean the cost in utilitarian terms? Basically, I'm buying an insurance policy for my house, if it's cheap, but the cost for utilitarians of saying we're never going to experiment on human beings, regardless of their mental abilities, is pretty small. In the experiments that I justified you conduct on rhesus monkeys and maybe occasionally, there's a human being whose mental capacity is lower than a rhesus monkey, so that's a cost, but it's a small cost.

My final conclusion is that, usually, if you are an insured utilitarian —a reasonable utilitarian, not a seventeen-year-old boy racer utilitarian—, then usually, you should just do what your theory says, but when you recognize that the costs of getting it wrong are massive and the benefits are small, when the benefits in this case are pretty small, then take out insurance. Don't do what Peter Singer recommends and conduct lethal medical experiments that are justified in terms of the consequences on human beings.

These are the examples of claims that get into the newspapers and they are exactly the examples of claims that utilitarians should be less confident about, and they wouldn't say these things.

What do you make about, what do I say to the allegation? That basically, to be a specialist is to be a racist. Here's a way to counter that. In utilitarian terms, perhaps that's true, that there is no difference between racism and speciesism, as in these arbitrary boundaries, but here's a big difference. It's a big difference that should be visible to less confident utilitarians, who are less obsessed about what their theory says, and more acutely interested in what other people say: I have never yet heard a reasonable presentation of racism. Moral racism: a reasonable presentation of the idea that, because my skin is light, I'm more morally important than people who have darker skin. I'm still waiting to hear a reasonable argument of that conclusion. I've heard many reasonable presentations of the idea that being a member of our species matters. It seems to me that I'm not compelled. I'd say, well look, of course, I'm an insured utilitarian, but I'm not mad. I'm not going to listen to the racists who haven't got good reasons at all, but I will listen to the reasonable people, so I'm not going to insure myself against racism just as I'm not going to insure my house against destruction by an extra-terrestrial death ray.

The conclusion is that Tipu Aziz is right. There can be a good utilitarian case for doing experiments on rhesus monkeys, but only a really massively over-confident utilitarian would say that we should perform those same experiments on mentally disabled human beings. I say no to that, and yes —not, obviously, for experiments on cosmetics, or things like that, that don't make a difference—, to the important stuff on animals, not on humans. ◗

4. SESSION OF THE COUNCIL OF THE CONBIOÉTICA

The Council of the National Bioethics Commission of Mexico (CONBIOÉTICA) held its XLVIII ordinary session in the 12th World Congress of Bioethics. The session was attended by its president, Manuel H Ruiz de Chávez, also with the participation of its members and the technical secretary Sandra Carrizosa and thirteen special guests:

- Amar Jesani, editor of the *Indian Journal of Medical Ethics*.
- Andrew Haines, Professor and former Director of the London School of Hygiene and Tropical Medicine.
- David Koepsell, Associate professor of philosophy at the Delft University of Technology.
- Francisco Javier León, President of the Latin American and Caribbean Federation of Bioethics Institutions and professor at the Pontifical Catholic University of Chile.
- Johannes J. M. van Delden, President of the Council for International Organizations of Medical Sciences (CIOMS).
- John Harris, Professor and Director of the Institute for Science, Ethics and Innovation (ISEI) at the University of Manchester.
- Jonathan Moreno, Professor at the University of Pennsylvania.
- Maria Casado, Director of the Bioethics and Law Observatory at the UNESCO and Chair in Bioethics at the University of Barcelona.
- Maria do Céu Patrão Neves, former Member of the European Parliament and professor at the University of the Azores.
- Peter Kemp, Professor emeritus at the Danish University of Education and executive director of the Center for Ethics and Law, Copenhagen.

- Michael Selgelid, Director of the Centre for Human Bioethics-Monash University.
- Simon Kawa Karasik, Director General of the Coordination of National Institutes of Health of Mexico.
- Søren Holm, President of the International Association of Bioethics.

The purpose of this meeting was to present the experts with the CONBIOÉTICA's work and to address issues that are of interest to Mexico and to this institution.

The meeting began with a brief participation by Doctor Ruiz de Chavez, in which he presented the audience a semblance of CONBIOÉTICA. The session discussed about three topics. Each one was presented by four of the guests. Jonathan Moreno and Michael Selgelid talked about bioethical design of public policies; Johannes (Hans) J. M. van Delden introduced at the bioethical discussion in contemporary research perspectives, and Maria Casado presented the main challenges of education in bioethics programs. Each presentation was followed by interventions of the participants.

The experts discussed about the origin of bioethics and its important role in the democracies since it offers a model for our political systems. The guests underlined the necessity that bioethics goes beyond health issues, but for research and respect to people, and even the impact on environmental policies. They also emphasized that nations should look for common standards in those issues.

In the opinion of the attendees, the political issues should be addressed as ethical issues, since they have a direct impact in society. The practical use of bioethics depends on the adequate information about the context, which calls for empirical questions of understanding and philosophical questions. Many people know about empirical or philosophical issues, but not many know about both and are not able to combine the two types of knowledge in a useful way: this is precisely the value of bioethics in the formulation of public policies.

It was noted that bioethics covers a wide range of activities. There are experts who provide advice on bioethics, some altruistically on various committees; however, this is a very different form of academic

activity. There is also the type of bioethics that strengthen legal regulation. When we talk about bioethics and its influence on public policy, it is very important to keep those three channels open.

The experts also talked about some issues regarding informed consent and the context in which it works on. There is a problem about information overloaded; if there is too much content in documents, then they become meaningless, people do not read them and signature becomes a mere formality.

They also talked about the contemporary challenge on research. They questioned the need for an increased focus on ethics in setting research priorities and funding thereof. It was also set whether the society is putting its limited investigative resources on the right issues; whether the investigation in public health and the economic health of the environment deserve better analysis. It was suggested that awareness should be promoted on the issue and that further discussion is required; not only if the research is possible, but if it is ethically acceptable.

One of the tasks for bioethics commissions is to generate debates within countries to discuss these issues and set priorities for the nation; otherwise it will be very difficult to build a just society with values and respect for the dignity and human rights.

The last topic addressed was the challenges in educational programs on bioethics. The experts emphasized the need for a training program not only to members of ethics committees, but also aimed at professionals and government officials from a multidisciplinary perspective, among others: law, social sciences, life sciences, philosophy, anthropology, ecology. They considered it is a necessity to bring bioethics to universities curricula and integrate this discipline as a specific subject.

They also mentioned challenges in creating and maintaining educational networks in a multicultural environment, and working together to overcome the problems: religious ideology and conflicts of interest are two of the most complex.

The session concluded leaving many core issues on which to reflect. This was the first time that the CONBIOÉTICA's Council hosted a meeting with international and renowned experts.

5. SATELLITE MEETINGS

As customary, with motive of the World Congress of Bioethics different groups, held conferences with issues related to those discussed during the congress, such gatherings are called satellite meetings. On this occasion, with support of the Congress' organizing committee, on 23, 24 and 28 June four satellite meetings were held:

- Feminist Approaches to Bioethics (FAB) Congress 2014
- Bioethics Workshop for Early Career Scholars
- Conference on Bioethics, Public Health and Peace for Indigenous People
- Revived Global Forum for Bioethics in Research ◗

5. 1 Feminist Approaches to Bioethics (FAB) Congress

The International Network on Feminist Approaches to Bioethics held their 10th world conference on June 23-24. This biennial conference has been taken place since 1996, usually at the same venue on date close to the FAB World Congress of Bioethics.

The FAB Congress was attended by approximately sixty experts from all over the world, some of whom also presented papers during the Congress.

For this time, the Congress theme was "Health Care Ethics: Local, Global, and Universal." During the two day conference, speeches delivered were related to Healthcare Systems, Abortion and Conscientious Objection, Mothering, Childbirth: Medical Tourism,

Clinical Research, Transnational Contract Pregnancy, among other topics.

In addition, the Donchin and Holmes Emerging Scholar Prize was delivered. It was established on the occasion of FAB's 20th Anniversary, the prize honored the co-founders of FAB, Anne Donchin and Helen (Becky) Bequaert Holmes. The prize was awarded to the best paper accepted for presentation at the FAB World Congress by a graduate student or early career scholar.

Also the FAB general meeting, and a reception for the International Journal of Feminist Approaches to Bioethics, hosted by Stony Brook University took place.

The FAB world congress ended with the FAB-IAB crossover session held on 25 June, in which Doctor Ruth Macklin talked about Health, Safety, and Women's Human Rights.

For more information about the International Network on Feminist Approaches to Bioethics, go to: http://fabnet.org/ ◗

5.2 Early Career International Bioethics Scholars' Workshop

The Early Career International Bioethics Scholars' workshop was conceived to provide a forum for scholars from low- and middle-income countries to receive training in conducting and disseminating bioethics scholarship. The participants had circulated draft papers and research proposals ahead of time. The day involved didactic instruction, discussion, presentation of projects by the scholars, and mentoring by peers and faculty members from the Clinical Center Department of Bioethics at the National Institutes of Health (NIH). In the morning, presentations by NIH bioethicists provided guidance in how to conduct conceptual research, empirical research, and how to develop a program of research. The group discussed the pitfalls and hurdles of developing a career in bioethics and collectively addressed specific challenges that the participants were facing. In the afternoon, the participants split

into small groups to discuss their work in progress. Each group was moderated by one of the NIH bioethicists and focused on providing constructive and critical feedback to facilitate future publication.

Participant research topics included:

- Research-related injuries.
- Informed consent.
- Post-trial obligations.
- Community Advisory Boards.
- Genetically-modified crops.
- The concept of vulnerability.
- Bioethics education.
- Networks of RECs.
- The presentation of people living with HIV/AIDS by the media.

Participants

Ten participants from low- and middle-income countries: Argentina, China, Colombia, Cuba, India, Malawi, Tanzania, Zambia, Zimbabwe. Nine of the ten participants also presented papers or posters at the World Congress of Bioethics.

Each of the participants is expected to produce a publishable paper as a result of the workshop. NIH mentors support the network of scholars from this and similar workshops in order to advance their bioethics research programs. ◗

5.3 Revived Global Forum for Bioethics in Research

The Global Forum on Bioethics in Research (GFBR) was held as a one-day satellite meeting at the 12th World Congress of Bioethics in Mexico City. The meeting was attended by participants from around 25 countries spanning six continents, primarily constituted of representatives from

low and middle income countries. It served as a re-launch of the GFBR and the theme was "The ethics of international collaborative research."

Re-launch

The meeting provided an exciting opportunity to take stock of where a revised GFBR fits in with current initiatives and debates in international research ethics and to ensure that in future, the GFBR provides the best platform for international dialogue, consensus building and resolution of key ethical issues in international health research.

It was agreed that the GFBR has a unique opportunity to widen the scope of interests and issues of global significance for the bioethics, research ethics and health research communities, allowing voices and perspectives from many different countries and continents to be heard and acted upon. Uniquely, it can provide a genuine environment for dialogue, allow the sharing of theory and evidence-based research and open opportunities for equal partnership between research groups from different institutions, countries and regions. Critically, the GFBR should stay focused on where it can make a difference to research practice around the world.

Discussions in Mexico also highlighted that in moving forward, it will be important to consider how to integrate the following into the GFBR model:

Substantive ethical issues: influencing research practice across the globe on issues such fairness, justice and global inequalities.

Agenda setting for research ethics priorities: enabling researchers in low and middle-income settings to determine what matters for their research ethics practices.

Applied focus: embedding the work, discussions and findings of the GFBR into policy and into practice.

Network Building: piloting models of short-term collaborative initiatives between participants of GFBR meetings.

Theme: *The ethics of international collaborative research*

Throughout the day, several key themes emerged in the presentations and subsequent discussions. A high level summary is outlined below.

Research Ethics Committee (REC) review

RECs form only one component of the ethical governance of research, but their efficacy, operation and efficiency are cited frequently as creating challenges for research. The role of RECs often extends beyond ascertaining whether a protocol has reached a threshold for constituting ethical research, into establishing compliance, legal oversight or administrative authority, with multiple layers of review but few standards or oversight mechanisms. A key question for considering how to improve ethics review concerns how to understand the REC process as part of a wider system that is responsive to the context of research, whilst continuing to safeguard the interests of participants.

Trust

In many settings, particularly those in which exploitation has been historically rife, research is hampered by deep levels of mistrust, both by the public and between bodies involved in the research process. Clear demonstrations of societal and health benefits, transparent structures of accountability and efforts to reduce imbalances in power between collaborative partners are essential to enabling trustworthy relationships to be developed.

The international research environment

International collaborative research brings with it a particular set of challenges, not least where there are power and finance differentials between partners in different income settings. Genuine partnership between researchers and participant communities require early engagement and understanding of local contexts. International consensus may be reachable on substantive ethical issues, even if the processes through which different communities approach these legitimately differ.

Communication and information sharing

Technological innovations are beginning to enable new communities of research practice to develop, not bounded by geography. Several initiatives already exist to support researchers, share capabilities and disseminate best practice in ethics review: it is likely that these will be increasingly useful tools for researchers across the globe

GFBR Inaugural Award

Finally, at the end of the meeting Doctor Ruth Macklin was awarded the inaugural Global Forum on Bioethics in Research Award for "Contributions to Progress in International Research Ethics" and received a commemorative trophy. The GFBR intends to make this an annual award for outstanding researchers in the field of international bioethics.

Conclusions

Ethics review processes continue to be a source of significant ethical and practical concern in many different contexts, and these challenges are often magnified in international collaborative research in which issues of power dynamics, trust and fairness come to the fore.

There may be different forms of ethics review sensitive to their particular contexts that can nonetheless achieve "equivalence" or "reliance agreements" and thereby adhere to the same standards. GFBR participants have begun to build tools for collaborative research and ethical review, and the GFBR could help to create networks of members to pilot different models or tools. Empirical pilot work needs to be done to explore how the right systems can be developed in different settings. This would ensure the GFBR is utilized as a way to take ideas forward for piloting and reporting back.

The GFBR could also potentially take a lead in developing key competencies for international research ethics.

For a full report of the meeting, go to: http://gfbronline.com/. ◗

5.4 Conference on Bioethics, Public Health and Peace for Indigenous People

This Conference was held all day on Saturday, 28 June 2014, at the UNAM, University Cultural Center in Tlatelolco, Mexico City. It was an official Satellite Meeting side event of the 12th World Congress of

Bioethics, and joined by 50 persons from around the world. The speakers came from many different nations, and stimulated discussion for all the participants to participate.

Bioethics is present in every community of the world in the relationships between people, plants and animals and nature. Indigenous Peoples are starting to rediscover their identities and philosophies. One part of this Conference was to examine the articulation of different ethical world views of nature, life and ethics, a second was how these are being applied to bioethical decision-making. A third part was to explore how these have, and could further contribute to, lessening the devastating public health divides inside and between many countries. There is a need to preserve the culture, traditions, health, welfare, and rights of Indigenous Populations throughout the globe. Indeed, health and public health are undisputedly foundational pillars of any sustainable community, society or nation and serve as positive attributes of peace. Finally was explored the links between public health and peace for Indigenous Peoples.

The Proceedings

After the welcome, and blessing of participants and thanks to the ancestral owners of the land, and self-introductions, there were presentations.

Professor Darryl Macer, American University of Sovereign Nations (AUSN), and Director, Eubios Ethics Institute, Thailand, New Zealand and Japan, spoke on Bioethics and Peace for Indigenous Peoples. The AUSN represents a monumental historic development: this project represents the development of the First-ever US Medical School and First-ever Master of Public Health (MPH) program to be located on Native American Sovereign Land.

AUSN has an expressed and dedicated commitment toward academic excellence, the pursuit of truth and social justice, the discovery of new knowledge through the attainment of the highest level of academia, scholarship, research, critical-thinking and analysis. AUSN is strongly based in the promotion of respect for human rights,

fundamental freedoms, peace, the sense of human dignity, and the promotion of understanding, tolerance and friendship amongst all nations and all peoples.

AUSN is deeply committed to offering excellence of education, academia and scholarship, through which we will, provide our students the intellectual freedoms and ability to rejoice in the discovery of critical thought and the pursuit of excellence. Provide our students the knowledge and the commitment required for full participation and service as future members and leaders of the learned professions; properly prepare future leaders of our communities who will be committed and vigorously engaged in helping those who suffer, are burdened by social injustices, or who are stricken by disease, and do so for the benefit of all peoples and populations; Help our students understand the sense of obligation of citizenship, and need for a requisite commitment to the promotion of human tolerance and understanding, human respect, integrity, and human dignity.

AUSN has an expressed and dedicated commitment toward academic excellence, the pursuit of truth and social justice, the discovery of new knowledge through the attainment of the highest level of academia, scholarship, research, critical-thinking and analysis. Our research includes clinical, public health and social science research. The Institute of Indigenous Peoples and Global Studies, directed by Professor Darryl Macer, Provost of AUSN, undertakes innovative trans-disciplinary research. In this regard, while many wise people have tried to improve life and health outcomes for Native American Nations since the colonization, we believe we can greatly enhance health outcomes through integrating the wisdom, traditions, and latest scientific knowledge of peoples from around the world, thereby enhancing the space for dialogue and learning between peoples for a more sustainable world.

After the presentations, there was General Discussion led by the Darryl Macer and Professor Marcela Martha Rodriguez Alanis, Director, Instituto de Investigaciones en Bioética, Monterrey, Mexico. Marcela said that we should treat indigenous peoples as ways of life, inspirations, not just sources of knowledge.

The participants said that they would circulate papers, and a book was planned when enough papers were prepared. Future meetings

would be held. Everyone was asked to share their lessons of the day, and there was much positive feedback. There was suggestion for joint research activities. There should not just be reflection on theory but on real problems and population problems. Materials such as a poster and information could also be prepared.

Darryl Macer thanked again the Instituto de Investigaciones en Bioética, Monterrey, Mexico for support, and the organisers of the World Congress for provision of the room in the UNAM University Cultural Center in Tlatelolco, which is in the grounds of an Aztec temple. Plaza de las Tres Culturas, is so called because in one city square you can see three different time periods of Mexico City's development mixed together: the pre-Hispanic Aztec temple grounds of Tlatelolco, the 16th-century Spanish Church of Santiago, and a modern 20th-century skyscraper, the University Cultural Center Tlatelolco for UNAM.

Participants agreed to share emails and establish a yahoo list serve. The yahoo list serve is open for anyone interested in these issues please email to indigenousbioethics-subscribe@yahoogroups.com.

For a full report of the meeting email to: dmacer@au-sn.com ◗

6. SYMPOSIA, ORAL & POSTER PRESENTATIONS

In addition to plenary sessions, the academic program included presentations of three different modalities:

- Symposia: a group of experts discussing specific themes during 90 minutes.
- Oral presentations: a 10 minutes individual presentation followed by 5 minutes of discussion.
- Posters presentations: a 5 minutes oral explanation of a graphical display (97 cm wide x 147 cm high) followed by 2 minutes for discussion.

The call for papers remained open from November 2013 to January 2014. On the congress website, a section to submit abstracts was available. As a result, 663 abstracts were received, most of which corresponded to oral presentations, followed by symposia and, finally, poster presentations.

To ensure quality and relevance of the academic program content, the abstracts received were evaluated by the Congress Scientific Committee members, consisting of experts in bioethics and related fields from all around the world. The abstracts were independently assessed and scored by two reviewers on a scale from 1 to 5 considering academic rigor originality and relevance. The review process was conducted electronically.

The assessment outcomes were notified to submitters through an official letter sent by email, which stated the results of the sent abstract: accepted or not accepted and, if applicable, the modality of presentation.

In addition to the Scientific Committee's approval, submitters had to complete the registration process, to guarantee inclusion of their abstract in the academic program.

Finally, the total amount of presentations delivered reached 418. The following table compares the final amount of entries filed and received:

Type of presentation	Abstracts Received	Abstracts Filed	% Filed vs Received
Oral presentations	485	290	60%
Symposia	82	50	61%
Posters	96	78	81%
Total	663	418	63%

Table 1. Abstracts received and filed for the 12th World Congress of Bioethics

Given the number of abstracts accepted, it was necessary to design an academic program that would arrange the presentations properly. Therefore, following the scheme carried out in previous editions of the conference, presentations were grouped according to their mode and theme in parallel sessions, sometimes reaching up to ten academic activities being carried out simultaneously.

Throughout all the activities of the Congress, there was participation of 538 experts, including participants within symposia, and individual oral and poster presentations. The following table shows the total amount of sessions and presenters according to the type of presentation:

Type of presentation	Sessions	Presentations/speakers
Oral presentations	44	290
Symposia	6*	170*
Posters	5	78
Total	55	538

*Speakers participating in 50 symposia

Table 2. Sessions and speakers during the 12th World Congress of Bioethics

6.1. Themes addressed

To properly arrange the approved abstracts, all were categorized according to their affinity.

To set the categories, the following methodology was used:

1. Consulting previous sources
The thematic classification made by the Scientific Committee of the 11th World Congress of Bioethics held in Rotterdam in 2012 was examined, also the papers were published in the abstracts book so as to identify the type of work entered in each category.

2. Reviewing accepted abstracts
Reading of the accepted abstract, identifying the theme and possible side issues.

3. Developing the thematic categorization for the 12th World Congress of Bioethics

a) The abstracts were gathered into categories based on the thematic classification of the 11th World Congress of Bioethics and the keywords assigned by authors when registering their work and identifying the primary and secondary topic.
b) In addition to the categories of the 11th World Congress of Bioethics, some other categories were created.
c) Given the number of papers reviewed, a grouping of specific themes was conducted in broad categories, which were used to review professional disciplines related to bioethics to reach a consensus on the category name.

As a result, 33 thematic categories were set, encompassing all the abstracts to be featured during the conference:

Thematic Categories		
1. Ageing	12. End of life	23. ICT and ethics
2. Animal ethics	13. Enhancement	24. Migration and healthcare
3. Begining of life	14. Environmental ethics	25. Multicultural ethics
4. Bioart	15. Ethics and policymaking	26. Neuro-ethics
5. Biobanks	16. Ethics Commitees	27. Pediatric ethics
6. Bioethics and evolution	17. Ethics of caring	28. Pediatric research
7. Bioethics and transplants	18. Food ethics	29. Reproductive technologies
8. Bioethics and vulnerability	19. Gender and health	30. Research ethics
9. Bioethics theory and methodology	20. Gender and reproduction	31. Sexuality and bioethics
10. Clinical ethics	21. Genetics	32. Social Bioethics
11. Decision-Making	22. Global Health	33. Teaching and Bioethics

Table 3. 12th World Congress of Bioethics thematic categories

The 50 symposia presented were grouped into 22 of the 33 established categories being *Bioethics theory and methodology* the most recurrent one.

The following table shows the top five thematic categories for symposium modality:

Themes for symposia		
Theme	Presentations	% of total presentations (50)
1. Bioethics theory and methodology	8	16.0%
2. Biobanks	4	8.0%
3. Clinical ethics	4	8.0%
4. End of life	4	8.0%
5. Global health	3	6.0%

Table 4. Recurring thematic categories for symposia presentations

The 290 oral presentations delivered were grouped into 22 of the 33 set categories, the most recurrent one was *Global health*.

The following table shows the top five thematic categories for the oral presentation modality:

Themes for oral presentations		
Theme	**Presentations**	**% of total presentations (290)**
1. Global health	38	13.1%
2. Clinical ethics	27	9.3%
3. Research ethics	24	8.3%
4. Ethics and policymaking	22	7.6%
5. Bioethics theory and methodology	19	6.6%

Table 5. Recurring thematic categories for oral presentations

The 78 poster presentations delivered, were gathered into 12 of the 33 set categories, for this case *Social bioethics* was the most common.

The following table shows the top five thematic categories for the poster presentation modality:

Themes for posters		
Theme	**Presentations**	**% of total presentations (78)**
1. Social bioethics	16	20.5%
2. Global health	8	10.3%
3. Research ethics	7	9.0%
4. Teaching and bioethics	7	9.0%
5. Bioethics theory and methodology	6	7.7%

Table 5. Recurring thematic categories for poster presentations

Categories and types of participation

	Thematic Categories	Type of participation							
		Oral presentations		Symposia		Posters		All presentations	
		No.	%	No.	%	No.	%	Total	%
1	**Global Health**	**38**	**13.1**	**3**	**6.0**	**8**	**10.3**	**49**	**11.7**
2	**Clinical ethics**	**27**	**9.3**	**4**	**8.0**	**5**	**6.4**	**36**	**8.6**
3	**Research ethics**	**24**	**8.3**	**3**	**6.0**	**7**	**9.0**	**34**	**8.1**
4	**Bioethics theory and methodology**	**19**	**6.6**	**8**	**16.0**	**6**	**7.7**	**33**	**7.9**
5	**Ethics and policymaking**	**22**	**7.6**	**2**	**4.0**	**3**	**3.8**	**27**	**6.5**
6	Social bioethics	7	2.4	2	4.0	16	20.5	25	6.0
7	Decision-making	17	5.9	1	2.0	4	5.1	22	5.3
8	Teaching and bioethics	11	3.8	1	2.0	7	9.0	19	4.5
9	End of life	10	3.4	4	8.0	3	3.8	17	4.1
10	Bioethics and vulnerability	9	3.1	2	4.0	4	5.1	15	3.6
11	Genetics	10	3.4	0	0.0	5	6.4	15	3.6
12	Biobanks	6	2.1	4	8.0	4	5.1	14	3.3
13	Animal ethics	11	3.8	0	0.0	0	0.0	11	2.6
14	Multicultural ethics	8	2.8	3	6.0	0	0.0	11	2.6
15	Pediatric research	10	3.4	0	0.0	0	0.0	10	2.4
16	Enviromental ethics	9	3.1	1	2.0	0	0.0	10	2.4
17	Reproductive technologies	6	2.1	2	4.0	1	1.3	9	2.2
18	Gender and health	9	3.1	0	0.0	0	0.0	9	2.2
19	Bioethics and transplants	6	2.1	2	4.0	0	0.0	8	1.9
20	Beginig of life	7	2.4	0	0.0	0	0.0	7	1.7
21	Enhancement	6	2.1	0	0.0	0	0.0	6	1.4
22	Gender and reproduction	3	1.0	1	2.0	1	1.3	5	1.2
23	ICT and ethics	5	1.7	0	0.0	0	0.0	5	1.2

Categories and types of participation

Thematic Categories		Type of participation							
		Oral presentations		Symposia		Posters		All presentations	
		No.	%	No.	%	No.	%	Total	%
24	Food ethics	3	1.0	1	2.0	0	0.0	4	1.0
25	Ethics committees	0	0.0	0	0.0	4	5.1	4	1.0
26	Bioethics and evolution	1	0.3	2	4.0	0	0.0	3	0.7
27	Migration and healthcare	1	0.3	1	2.0	0	0.0	2	0.5
28	Sexuality and bioethics	2	0.7	0	0.0	0	0.0	2	0.5
29	Neuro-ethics	2	0.7	0	0.0	0	0.0	2	0.5
30	Pediatric ethics	1	0.3	0	0.0	0	0.0	1	0.2
31	Bioart	0	0.0	1	2.0	0	0.0	1	0.2
32	Ageing	0	0.0	1	2.0	0	0.0	1	0.2
33	Ethics of caring	0	0.0	1	2.0	0	0.0	1	0.2
	Total	**290**	**100.0**	**50**	**100.0**	**78**	**100.0**	**418**	**100.0**

Table 5. Presentations delivered according to type and thematic category

The table above summarizes the thematic categories identified for the papers presented at the conference according to the mode of participation. Higher recurrence categories are highlighted.

The wide range of topics covered during the conference reveals the vitality of bioethics as a multidiscipline. As shown in the next table, there is not a dominant category and, in addition, there is similarity among the most frequent categories for symposia, oral and poster presentations.

It is noteworthy that by identifying the current issues in bioethics of academic interest around the world, we can see that *Global health* is the category that gathered the most abstracts presented, followed by *Research ethics* and *Clinical ethics*. Likewise, there was much discussion on methods and theory for bioethics. It can be said that, nowadays, the study of bioethics has broadened to include other topics and areas, as well as those classical on the field. ◗

6.2 Abstracts delivered by World Region

Even though the Congress was held in Mexico, and it was expected to have a greater number of participants from the Americas, the papers presented during the conference came from experts from around the world as shown in the table below.

The topics were addressed from different perspectives, which gave the event richness and diversity.

World Regions	Type of presentation							
	Symposia		Oral Presentations		Posters		Total	
	No.	%	No.	%	No.	%	No.	%
Africa	2	4	12	4.1	3	3.8	17	**4.1**
Asia	5	10	28	9.7	9	11.5	42	**10.0**
Europe	18	36	83	28.6	10	12.8	111	**26.6**
Latin America	1	2	57	19.7	20	25.6	78	**18.7**
North America	5	10	29	10.0	1	1.3	35	**8.4**
Oceania	4	8	15	5.2	1	1.3	20	**4.8**
Mexico	15	30	66	22.8	34	43.6	115	**27.5**
Total	50	100	290	100.0	78	100.0	418	**100.0**

Table 6. Presentations delivered according to World Region

The scope of themes addressed and the nationalities of the congress attendees and presenters made the 12th World Congress of Bioethics a truly international conference. The following table shows the abstract thematic categories by world region. It can be said that the specific subjects of bioethical interest change depending on particular contexts.

Themes per world region			
Africa		**Asia**	
Decision-making	3	Clinical ethics	6
ICT and ethics	2	Ethics and policymaking	5
Global health	2	Global health	5
Research ethics	1	Decision-making	4
Biobanks	1	Bioethics and transplants	3
Enhacement	1	Multicultural ethics	3
Enviromental ethics	1	Research ethics	2
Ethics and policymaking	1	Bioethics and vulnerability	2
Ethics Commitees	1	Bioethics theory and methodology	2
Multicultural ethics	1	End of life	2
Pediatric research	1	Gender and reproduction	2
Sexuality and bioethics	1	Social Bioethics	2
Teaching and bioethics	1	Teaching and bioethics	2
Total	**17**	Biobanks	1
		Genetics	1
		Total	**42**

Table 7. Themes and World Regions

Themes per world region			
Europe		**Latin America**	
Research ethics	13	Social bioethics	13
Global health	13	Research ethics	11
Bioethics theory and methodology	10	Global Health	8
Biobanks	10	Teaching and bioethics	7
End of life	7	Bioethics and vulnerability	4
Ethics and policymaking	7	Bioethics theory and methodology	4
Genetics	7	End of life	4
Clinical ethics	7	Clinical ethics	3
Decision-making	4	Gender and health	3
Animal ethics	4	Animal ethics	2
Gender and reproduction	3	Beginig of life	2
Pediatric research	3	Decision-making	2
Social bioethics	3	Enhacement	2
Teaching and bioethics	3	Enviromental ethics	2
Gender and health	2	Ethics and policymaking	2
Bioethics and transplants	2	Multicultural ethics	2
Enhacement	2	Pediatric research	2
Enviromental ethics	2	Biobanks	1
Reproductive technologies	2	Bioethics and evolution	1
Migration and healthcare	1	Ethics Commitees	1
Ageing	1	Food ethics	1
Bioethics and vulnerability	1	ICT and ethics	1
Ethics Commitees	1	**Total**	**78**
ICT and ethics	1		
Neuro-ethics	1		
Pediatric ethics	1		
Total	**111**		

Table 7. Themes and World Regions

Themes per world region			
North America		**Oceania**	
Global health	7	Bioethics theory and methodology	4
Research ethics	4	Decision-making	3
Decision-making	3	Clinical ethics	2
Genetics	3	Bioethics and transplants	1
Enviromental ethics	3	Enhacement	1
Reproductive technologies	3	Ethics and policymaking	1
Bioethics theory and methodology	2	Food ethics	1
Teaching and bioethics	2	Genetics	1
Ethics and policymaking	1	Global health	1
Ethics of caring	1	Multicultural ethics	1
Food ethics	1	Neuro-ethics	1
Gender and health	1	Pediatric research	1
ICT and ethics	1	Research ethics	1
Migration and healthcare	1	Social bioethics	1
Multicultural ethics	1	**Total**	**20**
Pediatric research	1		
Total	**35**		

Table 7. Themes and World Regions

Themes per world region

Mexico	
Clinical ethics	18
Global Health	13
Bioethics theory and methodology	11
Ethics and policymaking	10
Bioethics and vulnerability	8
Social bioethics	6
Animal ethics	5
Beginig of life	5
Teaching and bioethics	4
End of life	4
Reproductive technologies	4
Decision-making	3
Gender and health	3
Genetics	3
Multicultural ethics	3
Enviromental ethics	2
Research ethics	2
Bioethics and evolution	2
Bioethics and transplants	2
Pediatric research	2
Bioart	1
Biobanks	1
Ethics Commitees	1
Food ethics	1
Sexuality and bioethics	1
Total	**115**

Table 7. Themes and World Regions

7. CULTURAL ACTIVITY

Performance by the Mexican Folkloric Ballet of Amalia Hernández

The term "folklore" refers to a people or culture's traditional beliefs, practices and customs. These are traditions shared by different social groups that tend to be transmitted down from generation to generation.

Folk dances are one of the paramount manifestations of a country's folklore. Not only do they acknowledge, preserve and display the traditional habits, beliefs, rituals and customs of the inhabitants, but through their musical richness and the color of their movement and costumes they constitute an audiovisual spectacle that arouses a range of intense emotions in the audience, regardless of the origin, nationality or language of the latter.

The Mexican Folkloric Ballet shows this tradition in all its glory, since its origins in the 1950s, when Amalia Hernández, dancer, choreographer and founder of the institution, embarked on an untiring effort to recover Mexico's dance traditions.

The Mexican Folkloric Ballet has choreographed more than 120 dance performances. In all of them, the music, the technical rigor, the sumptuous traditional costumes and the original choreography combine to create the singular character of this company, whose international success for over more than sixty years has earned it numerous prizes and awards.

As part of the 12th World Congress of Bioethics cultural activities, an exciting performance by the Amalia Hernández Folkloric Ballet was featured. Throughout four decades, the Ballet has represented the country in the world, inspired by the diversity of Mexican folklore and seeking a representation through classical and modern dance techniques, carried out on stage with surprising results. This event was

held in the Library of Mexico, which was also adapted to hold the gala dinner for the Congress.

The seat of the library of Mexico: the *Ciudadela*, was originally built in the late 17th century to house the Royal Tobacco Factory of New Spain. In 1808 the building was reconstructed to permit a secondary use, to imprison the independence leader, José María Morelos y Pavón. During the Mexican Independence movement the building became a general artillery arsenal. In 1816 it ceased to be a tobacco factory to officially become the Ciudadela.

On January 30, 1940, President Manuel Ávila Camacho granted part of the Ciudadela building to the Library of Mexico, following negotiations by José Vasconcelos. The President and the Secretary of Education formally inaugurated the new library on November 27, 1946, with José Vasconcelos as its first director.

In 1987 architect Abraham Zabludovsky undertook a comprehensive renovation and restoration of the building. In 2011 the Master Plan for the Library of Mexico was started, intended to position it as a cutting-edge institution for the 21st century. It now stores the personal files of renowned writers, such as Carlos Monsiváis and Alí Chumacero, as well as it offers new services benefited from the innovative technological infrastructure.

The Library of Mexico houses several personal libraries donated by leading Mexican intellectuals and writers: José Luis Martínez Rodríguez; Antonio Castro Leal; Jaime García Terrés; Alí Chumacero and Carlos Mosiváis.

Finally, it also has a number of cultural spaces of prime importance: the writers' courtyard; the film courtyard; the "Octavio Paz" courtyard; the Abraham Zabludovsky gallery and the Alejandro Rossi bookstore.

http://www.balletfolkloricodemexico.com.mx/ ◗

8. CLOSING CEREMONY

Chair: Manuel H Ruiz de Chávez
Presidential Address: Søren Holm
Guillermo Soberón Travel Grant, Poster and Abstracts awards: Alex Capron and Medard Hilhorst
Next Venue: Edinburgh. Graeme Laurie and Nayha Sethi
Closing remarks: Manuel H Ruiz de Chávez

8.1 Presidential Address
Søren Holm

I'm going to give the Presidential Address. Preparing an address like this is not easy. I need to avoid platitudes, I need to be inspiring, I need to be, hopefully, academically rigorous and in the early evening, it also needs to be at least slightly provocative to keep all of you from falling asleep. I thought I would talk about some of the ways in which bioethical arguments can be so simplistic that they misfire, either directly or because necessary caveats concerning the scope of the conclusion are forgotten or left out.

I will talk about five things: about simplification and reduction, about bracketing, about what I will call the "ain't-necessarily-so" arguments, the irresistible attraction of the hole-in-one argument, and finally the grand leap of the whale. I will be happy to hear from anyone with ideas to how these five can be extended into the requisite seven to count as the Cardinal Sins of Bioethics. I could have illustrated all of these problems from my own work, but my illustrations will mostly be from other people in the field, and my quotes in the talk will be anonymous except when I quote Plato, Benjamin Franklin and Beauchamp and Childress. My examples will come from a range of various bioethics.

The simplistic forms of arguments that will be in focus here are most frequently found in the short-form version of the *bioethics game*, the journal article, but it can be found in the long-form game, a book, as well. The proportion in journal articles is easy to explain since the short form of the journal article makes it difficult to explore all the ramifications of particular arguments. Simplification is necessary but it can go too far.

Let's start with simplification and reduction. Many issues in bioethics are messy and complicated. The first thing that any self-respecting bioethicist would do is to bring some order to this messiness. Can we define more precisely what the issues are? Who the legitimate stakeholders are? What values, rights, principles that are involved? Can we reduce the problem into components? Can we identify the premises in the arguments? Etcetera. This is all well and good, and necessary if you want to fit in with requirements of the major journals, but it can go too far.

When it goes too far, it's often because we try to identify *the* problem or *the* core problem and exclude all the other problems related to the issue at hand. There's always reason to be suspicious when you read the phrases, "the problem is" or "the core problem is" in bioethics literature. We have no *a priori* reasons to believe that there always is *a* core problem, and the work on *prima facie* principles and considerations, not to mention for a particular reason, or to make us wary of working too hard to find the core problem. But for some reason, it sounds like a plausible analytic strategy. We can raise statements like this, "In making this assessment the core problem presented by the patent ability of DNA must first be identified." But I submit to you that it really is not clear that there is a core problem here, and that it is a sensible move to try to identify it. Even if there is one, we might not agree on what it is. The *core problem strategy* creates problems in a number of ways. We may have simplified the way too much so that our analysis is not really an analysis of the problem at hand, or we may have fastened our attention on something which no one else thinks is a core problem.

The next problem I want to talk about briefly is bracketing. Bracketing occurs at least in two forms in bioethical arguments. The first is common in discussions of new technologies that are not yet in

common use. What is bracketed, often already in the introduction, is any question about the effectiveness or side effects of the technology and we are invited to assume, "of course, just for the sake of arguments," that the mere technical issues have been solved. We can find this even in the title of papers. When I was preparing this talk I found this wonderful paper title, "Human cloning, public policy: [and it's my emphasis] when cloning is safe and effective?" Please note the use of "when," not "if."

Now, the other common type of bracketing occurs when, despite our best philosophical efforts, we have not been able to reduce a complex problem to only one issue, but we have to admit that there are two or maybe even three ethical problems or issues still at stake or that in the middle of an issue there is a contentious concept. Here there is a temptation to bracket one of the issues, again, "purely for the sake of arguments," and we will say or write things like, "let us assume," "let us accept," or "I will assume for the sake of argument." This can either be done directly and explicitly or by reference to some publication that is supposed to show that the problem can be easily overcome.

I think the most common type of this type of bracketing is that of justice concerns in relation to new technologies and potentially exploitative healthcare practices. In an article about kidney sales, we read, for instance, "another familiar objection is that it is unfair for the rich to have privileges not available to the poor. This argument, however, is irrelevant to the issue of organ selling as such. If organ selling is wrong for this reason, so are all benefits available to the rich, including all private medicine, and for that matter, all public probation of medicine in rich countries, including transplantation of donated organs that is unavailable in poor ones."

Now, what are the problems with bracketing? Well, if we take the first kind of technological bracketing, "when cloning is safe and effective?" The first problem is that it does, as all of its arguments rely on the care for its really being perfect for the argument to be valid and the conclusions to be sound. But we have ample illustration from medical history that there are very few technologies that are perfect. Most are imperfect, both in terms of effectiveness and in terms of harmful side effects. Few mature technologies and medical procedures

are completely safe and perfectly effective. The situation we'll most often find ourselves in is a situation where the procedure is relatively safe and relatively effective. Because these practicalities are bracketed in an argument, we therefore have a piece of applied ethics research that is not really applied in any meaningful sense, and is of little use to a policy maker.

Now, considerations of public policy, when cloning is safe and effective, are of little use to anyone at the present time, and probably, of any use to anyone ever. The problem with the second kind of bracketing is that our analysis will be incomplete and our conclusions only conditionally sound. If we have bracketed just these issues, then the only thing we can say with certainty is that if these are not significant, then our conclusion follows. If we, for instance, look at this quote concerning organ sales, again, then we can agree with everything that is said, but still point out that some privileges may be more unfair than others and that we need what we need as an analysis that tells us something about this particular privilege and whether it is ever likely to be extended to everyone or even most people.

The next argument I want to look at is the "ain't-necessarily-so" argument. When someone claims that "x" is morally problematic or morally good in a specific way, a common argumentative strategy in bioethics is to find the counterargument which shows that "x" is not necessarily connected to a morally-good or morally-bad making factor. In the research ethics literature we can find arguments which, in my view, shows that exploitation is not necessarily bad. There are examples of morally acceptable exploitation: being a member of the IRB Board may perhaps be a case of ethically acceptable mutually beneficial exploitation. And in the discussion about selection and reproduction, the arguments showing that selection for or against a certain trait is not necessarily expressive of any particular attitude towards their traits. That is, aborting a fetus with a particular disability does not necessarily express any views, attitudes, and opinions about that disability or about those who currently live with it. Again, I think that this argument is correct.

The problem with "it-ain't-necessarily-so" arguments is that the conclusion that "x" is not necessarily morally problematic is fully compatible with the view that most instances of "x" are morally

problematic or with the whole view, and even if not every instance of "y" expresses something, it is compatible with most of the view. If you publically burn the flag of my native country, Denmark, you do not necessarily express any views about Denmark. You may be engaging in performance acts; you may be protesting against free speech restriction, you may have mistaken the Danish flag for the Basque flag or the Swiss flag and many other possibilities. But the fact that you can burn the Danish flag, which incidentally is the oldest national flag in the world, without expressing a negative evaluation of Denmark, does nothing to show whether or not most people who have burned the Danish flag recently express certain attitudes.

And the "ain't-necessarily-so" arguments are particularly problematic when their scope is extended from actions by individuals to issues of public policies. Policies often express evaluations because those evaluations are made explicit in the policy process. When the Kenyan Parliament recently decided to legalize polygamy and decided that a man should not be required to tell his wife, or wives, that he was taking a new one, my argument would be that the policy expresses something about, primarily, male Kenyan politicians' views about women.

Let's move on to the irresistible attraction of the hole-in-one argument. The hole-in-one argument is an argument that solves a particular class of problems and all of them in one fell swoop. The classic discussion of hole-in-one arguments and where Peter Milligan first used the term, the paper in 1992, arguments about the moral status of human entities, arguments that are routinely employed by each side in debates about reproductive issues and end-of-life issues. On the conservative side we have a hole-in-one argument of a related to dignity-based kind, which essentially says that all humans have a Right to Life and, on the other side of the argument, we have the well-known personal arguments which essentially show that fetuses, embryos and so on, do not have a Right to Life. These are both arguments, which according to the proponents, solve almost all problems in relation to ethical issues at the beginning of life, or if not all, then on the conservative side, all when combined with the Catholic/Aristotelian unity of the act argument, and on the liberal side, with Parfit's non-identity problem. These arguments also solve all problems at the end of life.

I've been interested in these arguments for a long time. I wrote my Master's thesis supervised by John Harris, in 1990. I've discussed this with him ever since. I will look at two new hole-in-one arguments; that are both relevant to big data and to biobanking research. The first of these is what I will call privacies-obsolete arguments. The privacies-obsolete arguments solve many, perhaps all problems about the use of data in research on the basis of the claim that it is impossible to predict your privacy in the digital age against the determined agent wanting to find out your secrets, and that you should therefore give up any concerns you have about your privacy or alternatively that we are allowed to give no way to these concerns. I've probably caricatured the argument here, but even if stated more gracefully and benefiting from an application of some principle of charity in interpretation, I think it's rather suspect. It is probably true that the NSA and the CIA could find out everything about me that they wanted to find out, even that is only approximately true, but my concerns about my privacy, given that I'm not an international terrorist, are not primarily about what the CIA knows or could know if it bothered to investigate me, but what my neighbours, my colleagues, and my bank know. I don't think that I have any big skeletons in the closet, but lots of us have some small ones that we don't want to have publically exposed.

The privacies-obsolete arguments at least partially trace on an equivocation between two distinct questions, the first being can I have the kind of privacy I want? Which is essentially privacy against public knowledge, not privacy against the CIA; and, should I bother about this kind of privacy? It might well be that I should not bother. That is not because I cannot have what I want, but for separate reasons unrelated to the claimed impossibility of getting it.

There's an argument in the research ethics debate, which is of even larger scope and even better hole-in-one argument, this is the everyone-has-an-interest-in research argument, because if true, its scope covers not only big data research but also all research. This argument, correctly in my view, identifies that everyone of us has an interest in good research taking place, but then goes on to claim that, because we all have this interest, any kinds of waning interests we have are in general outweighed and that research regulation can be developed on that assumption. This would clearly solve a lot of

regulatory problems for dropping scientists in one fell swoop. The great attraction of the hole-in-one argument is its broad scope and radical disruptive power and perhaps more pragmatically, that once I've discovered one, I can write an endless number of articles exploring its implications, but that attractiveness comes at a price. The price we often have to pay when we employ hole-in-one arguments is that nuances tend to get lost and that we are tempted to define the problem in terms of the argument and not the other way around. Before we know what argument we are going to make, we are fitting our problem so that it fits with the argument.

The second problem is that if you employ hole-in-one arguments, you are unconvincing to your opponents. The final issue I want to draw your attention to is a quite magical conjuring trick that many of us are adept at performing. It is in many ways like the grand leap of the whale off the Niagara Falls, which is quite brightly described by Benjamin Franklin, from whom this quote is from, "as one of the finest spectacles in Nature." Franklin was writing on the bounties of the colonists as it were then, this is from 1765, and here about whaling, "Whales, when they have in mind to eat cod pursue them wherever they fly, and that the grand leap of the whale in the chase up the Fall of Niagara is esteemed by all who have seen it, as one of the finest spectacles in Nature." I'm certain that if anyone ever saw the grand leap of the whale up the Fall of Niagara it would be a truly magnificent spectacle.

The bioethical version of the grand leap of the whale is the instant conversion of philosophical conclusions to policy prescriptions. Despite what Plato might have thought in the Republic, there is little evidence that philosophers make good policy makers. There are very significant differences between the two activities of philosophy and policymaking. This is not a new observation, and the reasons were succinctly summarized by Beauchamp and Childress in the fifth edition of the *Principles of Biomedical Ethics*. "Public fallacies often formulated in contexts that are marked by profound social disagreements, uncertainties and different interpretations of history. No body of abstract moral principles and rules can determine policy in such circumstances, because it cannot contain enough specific information or provide direct and discerning guidance. Specially, specification and implementation of moral principles or rules must take into account the

problems of feasibility, efficiency, cultural pluralism, political procedures, uncertainty about risk, non-compliance by patients and the like." However, bioethicists sometimes do seem to at least imply that the philosophical analysis should directly be implemented in policy.

On these grounds, the fact that the fetus has a potential to become a person who will have an at least acceptable life is not reason for prohibiting abortion. This is a philosophical conclusion. Therefore, we argue that when circumstances occur after birth such that they would have justified abortion, what we call after-birth abortion should be permissible. Now, if this should be permissible here is not a philosophical conclusion, but a policy conclusion. But it follows in no way straightforwardly even if the underlying philosophical analysis is accepted. There are, for instance, many different instances of theft that are philosophically permissible, perhaps even mandatory, but it does not follow that all or any of these should be made explicitly permissible in law, or to take another example, I tend to agree with those who believe that many plastic surgery practices are oppressive and exploitative, but much further argument of a policy nature is needed before those philosophical conclusions can be turned into a policy conclusion.

The grand leap of the whale is also problematic for the further reason already alluded to by Beauchamp and Childress. Ethical arguments are, like all arguments, sound when they are valid and when the premises are true, but in ethics we are often in a situation where some of the premises are contested. The argument is also only conditionally sound: it is sound for those who accept the premises. This is not a problem if we can show that you have to be perverse; here I use the technical sense of perverse, not to accept them, but this is often not the case. As reasonable plurality concerning values and principles in this room, there's reasonable plurality in society and we can legitimately disagree even about quite fundamental things. If we go back to the abortion infanticide example, we do, for instance, have no good reasons to believe that everyone who accepts that women should have a legal claim right to publicly-funded abortion on demand for early abortions accepts this for the same reasons. To torture the metaphor even more: we don't even know whether our whales are swimming in the same rivers before we try to make them jump.

I should, perhaps, end my talk by exonerating Plato. There might be people in the room who would otherwise take me to task, because Plato clearly states in Book VII of the *Republic* that it is only after having distinguished themselves at many other tasks that persons are ready to do philosophy and to rule. This is from the Jagger translation, "When they've reached fifty years of age, then let those who still survive, and have distinguished themselves in every action of their lives and in every branch of knowledge, come at last to the consummation: the time has now arrived at which they must raise the eye of the soul to the universal light which lightens all things and behold absolute good; for that is the pattern according to which they are to order the State and the lives of individuals, and the remainder of their own life also; making philosophy the chief pursuit but, when their turn comes, toiling also at politics and ruling for the public good, not as though they were performing some heroic action, but simply as a matter of duty; and when they have brought up in each generation others like themselves and left them in their place to be governors of the State." Perhaps part of our problems, this might relate to Nick's seventeen-year-old drivers, are caused by the fact that we begin our bioethical careers far too early. Now, I'm just old enough, in Platonic terms, to make philosophy my chief pursuit, but I'm not certain that I have the distinguished and multi-faceted background that is a requirement to be allowed to do so. ◗

8.2 Prizes and awards

The *Guillermo Soberón* travel grant

The National Bioethics Commission of Mexico, as Organizing Committee, offered ten travel grants to attend the 12th World Congress of Bioethics, June 25-28th, 2014, in Mexico City.

Consistent with its mission of developing and promoting a bioethical culture at a global, regional and local scale, CONBIOÉTICA supported persons from all over the world to participate in this meeting.

The World Congress represents a unique opportunity for those attending to exchange opinions, information and experiences, and to discuss leading issues in bioethics. This travel grant was addressed for people from developing countries and covered round-trip airfare, accommodation and lunch costs.

The aim of the Guillermo Soberón Travel Grant is to support and promote the discussion of bioethics worldwide; to seek common understanding and (potentially) responses to contemporary issues; and to enhance the capacity of ethical reflection in all knowledge fields. The Travel Grant was an initiative from CONBIOÉTICA, but it had the support from the National Council of Science and Technology, and was named after Doctor Guillermo Soberón, former president of CONBIOÉTICA, who has promoted a bioethical culture nationwide.

Given the number of applications (41) and the quality of papers, the Organizing Committee had to make hard choices, in order to select the ten winners of the grant.

Recipients of the Guillermo Soberón Travel Grant

Name	Institution	Country
Mukadder Gun	Turkish Gendarmerie General Command	Turkey
Gloria Inés González Ramírez	Universidad Tecnológica de Pereira	Colombia
Godfrey Tangwa	Cameroon Bioethics Initiative (CAMBIN) / University of Yaounde	Cameroon
Haihong Zhang	Health Science Center, Peking University	China
Katya Marion Rodríguez Sánchez	Universidad Central del Ecuador	Ecuador
María Florencia Santi	Consejo Nacional de Investigaciones Científicas y Técnicas/ Universidad de Buenos Aires / Facultad Latinoamericana de Ciencias Sociales	Argentina
María del Sol Terlizzi	Consejo Nacional de Investigaciones Científicas y Técnicas/ Universidad de Buenos Aires / Facultad Latinoamericana de Ciencias Sociales	Argentina
Michel Daher	Lebanese National Committee for Ethics and Bioethics	Lebanon
Peter Osimiri	University of Lagos	Nigeria
Tang Jian	Institute of Medical Humanities, Peking University	China

The *Mark S. Ehrenreich Prize in Healthcare Ethics Research 2014*

Presented by Alex Capron

The *Mark S. Ehrenreich Prize in Healthcare Ethics Research 2014* was bestowed by the Pacific Center for Health Policy and Ethics at the University of Southern California, in conjunction with the International Association of Bioethics.

The importance of this prize, first of all, is that it clarifies the understanding of the concepts surrounding "public health," as it exposes and explains the claims inherent in key works in public health ethics, and develops and defends a particular understanding of the study of public health policies and practices.

This prize examines important works of moral, public health, public health law and ethics, and bioethics, and was aimed at scholars involved in health, who have proposed a paper for presentation at the Twelfth World Congress of Bioethics.

The winner of this prize received 1,500 US dollars.

Mark S. Ehrenreich Prize in Healthcare Ethics Research 2014 Results

	Abstract	Author	Country
Winner	Global Justice and Health Systems Research in Low and Middle-Income Countries	Bridget Pratt and Adnan A. Hyde	United States of America

The *MH-Poster Prize*

Presented by Medard Hilhorst

The *MH-Poster Prize* was delivered to the best and future-oriented posters presented during the Congress. This prize is an initiative of the Department of Medical Ethics and Philosophy of Medicine at the Erasmus Medical Centre in collaboration with the Dutch Fund to promote clinical medical ethics.

The criteria for the selection were originality, rigor and beauty, and it was assessed by the jury conformed by Professor Leonardo Di Castro, from the Bioethical Centre of Singapore; Doctor Siobhan O'Sullivan,

Bioethics officer at the Department of Health of Ireland; Doctor Alies Struijs from the Netherlands Centre for Ethics and Health; and Doctor Medard Hilhorst from the Erasmus Medical Centre in the Netherlands.

The posters had a significant impact at a global level. That's the spirit of the poster prizes. This time there was a tie for the winner, who had to split the 1,000 US dollars' first place award, and the runner-up received 350 US dollars.

MH-Poster Prize 2014
Results

	Poster	Author	Country
Winner	Normalcy and Normativity	Richard Joyce	New Zealand
Winner	Non-Invasive Prenatal Testing: an "Option" to Test or a "Pressure" to Test?	Hazar Haidar and Vardit Ravitsky	Canada
Runner-up	New Family Configurations	Gricelda Moreira, Adriana Ruffa, Graciela Soifer, María Laura Ferrari and Laura Andrea Massaro	Argentina

8.3 Next Venue: Edinburgh*

Graeme Laurie: Dear colleagues, good evening. My name is Graeme Laurie. I am Professor of Medical Jurisprudence and Director of the Mason Institute for Medicine, Life Sciences and the Law at University of Edinburgh, Scotland. I'm joined by the Mason Institute Deputy Director, Nayha Sethi. On behalf of UK IAB 2016 Organizing Committee we are proud to announce that Edinburgh will host 13th World Congress of Bioethics.

En primer lugar queremos agradecer a nuestros colegas mexicanos por un congreso muy bien organizado y muy difícil de imitar. Felicitaciones.

Nayha Sethi: Dear colleagues, as Graeme has just said, we would like to start off by congratulating our colleagues here in Mexico on having produced a wonderful 12th World Congress. It's going to be very,

very difficult for us to follow, but we are going to do our best. So, the Organizing Committee of IAB 2016 is led by the Mason Institute, based at the University of Edinburgh. Other members of the Organizing Committee come from the University of Birmingham, Queen Mary University of London, and St George's University of London. Together we are developing an exciting programme for IAB 2016 and we are hoping to explore what bioethics can contribute for individuals, for public interests and public goods. We believe that Edinburgh is the perfect venue to explore these issues. Let's take a look at why.

Video:* Global environment is changing rapidly. Shifts in science and technology demand that bioethicists rethink the role of the individual and the public good. Medical advances have brought into question what it means to be an individual. Genetic research, globalization, scarce health resources, climate change, many issues are applied in considering the public interest as vital. How can we contribute? By challenging perspectives. By understanding our duties to future generations. By exchanging knowledge and promoting understanding. By educating, debating and innovating, by pushing the boundaries to the known and the unknown. By encouraging cultural expression and collective development. Bioethics builds a bridge between leaders, practitioners, and decision-makers. Edinburgh, the city of great minds: Charles Darwin, James Young Simpson, Alexander Fleming; a place rich with culture, where art and science connect, heart of the Scottish Enlightenment: Adam Smith, David Hume. We are global leaders in research development, whether it's medicine, genetics, and stem-cell research and cloning, Edinburgh is in the foreground. Edinburgh, the ideal place for IAB 2016. Here, tradition and innovation meet. Individual and the public become one. Here, we will continue the global dialogue. Building bridges. This is a new Enlightenment.

Graeme Laurie: We are also delighted to welcome to the stage our dear friend and fellow Scot, Alastair Campbell, who's well known to this community, and Alastair has very kindly agreed to act as a consulting expert for IAB 2016.

Alastair Campbell: Well, *lasses* and *lads*, ladies and gentlemen, and my dear friend Manuel. We've had wonderful fun here in Mexico

* Video available on electronic version of this book

and a wonderful conference and I can promise you in Edinburgh you'll have plenty more fun and plenty more conference. We are proud of the fact that we are the home of the Scottish Enlightenment. We're the home of the Edinburgh Festival of Arts, we're a place vibrant with medicine and science for many generations, but I think above all, the thing I love about my native city and my native country is that we just like people. So, we want to welcome you, and we really will welcome you. Have a look at our website, express your interests in what you would like us to do in Edinburgh in good health and we'll see you in Edinburgh 2016.

Graeme Laurie: Alastair mentioned the importance of the Enlightenment in Edinburgh and what we would like to spark with this conference in 2016 is the new Enlightenment, where we can build bridges between different disciplines and different perspectives and where we can understand where the scientific knowledge has taken us and where it will take us in the future. So, let's look a little bit more at the details of what we hope to deliver for you in Edinburgh in 2016.

We'll do this through three distinct and interconnected strands. First, there will be a thought-provoking academic programme where you'll hear from exciting leaders in the field. Second, there will be a cutting-edge arts programme exploring the unique intersection between sciences, humanities and the arts to better understand issues in health, medicine, ethics and law, and their effect on individuals and the society.

Nayha Sethi: And our third strand is in recognition of the very important role which early-career researchers play in the international bioethics community. So, we are developing a dedicated programme of activities for junior academics, including interactive workshops on career progression and academic writing, grant writing, sessions where we can meet professors and, of course, we will have a vibrant social programme.

Del mismo modo como nuestros amigos mexicanos saben hacer la fiesta con tequila, nosotros sabemos hacer lo mismo muy bien con whisky.

Graeme Laurie: IAB 2016 is going to be about progress and capacity building, and we want to invite all of you to be an important part of how that programme takes shape. So, not only do we invite you to join us to present your papers and to take part on all these activities, but

we also want you to shape the sessions and the events and for them to meet your needs and your expectations. So, our dedicated website is already live, iab2016.com, and that would provide you with all of this information and development, and will serve as a hub for ideas and discussions ahead of the event. We want you to tell us what you want from IAB 2016. At the moment, you can fill in your expressions of interest on the website, and calls for abstracts will be live in the next few months, and don't forget to keep up with the excitement on #iab2016 where you can find out everything that's developing.

Thank you very much and we'll see you in Scotland!

¡Hasta la próxima!

For more information about the 13th World Congress of Bioethics visit http://www.iab2016.com/ ◗

8.4 Closing remarks

Manuel H Ruiz de Chávez

The 12th World Congress of Bioethics, held in Mexico City, has been prodigious in more than one sense, because it has merited the magnificent attention of countries from all continents, with their very different histories, cultures, knowledge and visions.

Our country is proud of this deeply committed response, and celebrates the global concern it shows for the dignity of all forms of life and their environment.

We have reached the end of this Congress. After three days of intensive work, we have far exceeded the goals we established for ourselves. More than 1,200 conferees from 72 countries have participated in more than five hundred academic activities during eight plenary sessions we witnessed thirty key note lectures, all excellent; fifty symposia held in four parallel sessions were presented; also 44 abstracts sessions, in which about 290 papers were presented and 78 posters were held in five sessions.

Similarly, it is worth noting the development of the four Satellite Meetings: the Feminist Approaches to Bioethics Congress, the, Global Forum for Bioethics in Research, The Bioethics Workshop for Early Career Scholars and the Public Health and Peace for Indigenous Peoples which will be held tomorrow at the premises of the Cultural Center Tlatelolco of our nation's highest educational institution: the National Autonomous University of Mexico.

But it is not just the figures that lead me to declare this meeting a resounding success. It has also been noteworthy for the depth and richness of the discussion of the various themes under which this great dialogue has been organized: global health, science, society and the individual. This clearly attests to the vitality of our discipline, or rather, multi-discipline, of bioethics.

All the speakers at this Congress have given us ample motive for reflection, and these in turn give way inevitably to challenges, commitments, and pending challenges in the world in which we live.

For Mexico, it has been a great learning experience, and a source of tremendous pride, to have the decisive participation of each and every one of you.

I believe the World Congress has been a propitious forum for pursuing the general aims established, and above all, for promoting bioethical knowledge as an expression of culture, and as an instrument for social development and collective welfare.

Nevertheless, we must continue promoting the social transcendence of bioethics and its repercussions in the daily lives of our citizens, and working to formulate effective public policy that traverses all areas of social development.

We are confident that the 12th World Congress of Bioethics was a splendid opportunity to create and strengthen the International Association of Bioethics. This meeting have incorporated many new members that will give new impetus to this institution. This was a good opportunity to strengthen and create new bonds of friendship between us.

It is my wish that this Congress serve as a point of departure for many transcendent projects and collaborative schemes in the multidisciplinary field of bioethics.

In Mexico, for our part, we are left with one commitment: nourishing the seeds planted by this Congress. All those who attended from the local bioethics commissions, our hospital committees on bioethics and research ethics committees, academics and students, share a responsibility to disseminate and cultivate the knowledge and achievements of this Congress, to enrich and strengthen bioethical culture in Mexico.

I'd like to express my gratitude to Doctor Mercedes Juan, Mexico's Secretary of Health; the National Science and Technology Council; the University Program on Bioethics of the National Autonomous University of Mexico, and especially my friends Inez de Beaufort and Angus Dawson.

We are pleased at the success of yesterday's cultural activities, that offered all of you a sample of the tremendous wealth of Mexican culture through this country's most renowned folkloric ballet. This event was made possible by the National Council for Culture and Arts, the Amalia Hernández Folkloric Ballet Corps, the Office of International Affairs at the Secretary of Foreign Affairs, the General Directorate of Libraries, the Museum of Popular Art, and the National Fund for the Promotion of Handicrafts (FONART) and our sponsors Casa Cuervo and Café Punta del Cielo.

I hope that, like me, you will hold this meeting in your memory and remember that Mexico awaits you with open arms.

Finally, I'd like to publicly recognize all my colleagues from the National Bioethics Commission of Mexico, whose efforts are manifested in the success of this meeting.

I wish our friends in Edinburgh the best of success. I must tell you that you are in for a period of arduous work —as I was warned in turn by Inez de Beaufort— and which will require a tremendous collaborative effort on all of your parts, but it will also be highly gratifying. I am happy to place at your disposal all the experiences and documents accumulated in the process of organizing and carrying out this Congress.

Many thanks, my colleagues and friends. We will meet again at the Thirteenth World Congress in Edinburg in 2016. Remember that the future calls us to "Inspire the Future to Move the World." I wish you safe travels on your return home, and many thanks for joining us here in Mexico. ◗

CONTRIBUTORS

Mercedes Juan

Secretary of Health, Mexico

Mercedes Juan was born in Mexico City. She holds a degree in Medical Surgery specialized in Rehabilitation Medicine at the National Autonomous University of Mexico (UNAM), with Postgraduate studies in Neurological Rehabilitation by the Metropolitan Autonomous University (UAM). Her professional development has been closely linked to public health.

The Secretary of Health was the first woman to achieve prominent positions in this sector, including being the first Secretary of Health Regulation and Development of the Secretary of Health and Secretary General Health Council, a constitutional body appointed by the President of Mexico. Mercedes Juan is a woman committed to her convictions and, as the first woman to head the Department of Health has offered to work as it always has, with care and dedication in order to ensure that public health services provide timely, warmth, quality and efficiency, as well as a great effort for prevention.

Manuel H Ruiz de Chávez

President of the Council, National Bioethics Commission of Mexico

Dr. Ruiz de Chavez received his medical degree from the National Autonomous University of Mexico (UNAM); Master of Science in Social Medicine by University of London, the London School of Hygiene and Tropical Medicine, as well as a Certificate by both Family Medicine and Public Health boards of Mexico.

Professor of Public Health of Family Medicine at the Faculty of Medicine at UNAM.

His professional career started around 35 years ago and has assumed various positions in the area of public health, health research and primary care, both at the national and international level.

Dr. Ruiz de Chavez is Member of the Royal Academy of Medicine in Spain, member of the Catalonian Royal Academy of Medicine and Fellow of the Royal College of Physicians of London, former President of the National Academy of Medicine and The Mexican Health Foundation.

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Consultant, researcher and teacher in bioethics and public health
Dr. Amar Jesani is an independent consultant —researcher and teacher— in bioethics and public health. He is one of the founders of the Forum for Medical Ethics Society and editor of the *Indian Journal of Medical Ethics*. He was involved in the organization of four National Bioethics Conferences (2005, 07, 10, 12) of the IJME. He is also one of the founding trustees of the Anusandhan Trust, which manages the health research institute CEHAT (Centre for Enquiry into Health and Allied Themes in Mumbai, and the health action institute, SATHI, in Pune in India. Presently he is working as a consultant and Co-PI of the Welcome trust supported research project titled *Investigating Reproductive Ethics-In-Context: The Indian Experience* with the King's College, London. He is visiting professor teaching bioethics at the Ethics Centre, Yenepoya

University, Mangalore, India (since 2011) and the Centre for Biomedical Ethics and Culture at the Sindh Institute of urology and Transplantation in Karachi, Pakistan (since 2010).

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The London School of Hygiene and Tropical Medicine
Andy Haines was the London School of Hygiene and Tropical Medicine's director from October 2001 until 2010. He was responsible of 3,700 postgraduate students and more than a 1,000 employees. Before that he was the primary Health Attention professor and chief of the Primary attention and population science´s department of the University College of London. He was an epidemiologist consultant in the Epidemiologic Unit of the Medical Assistance and Investigation Counsel. Moreover, he was. Director of Investigation and Research of the National Executive Health Services, North Tames and a member of the counsel as well the strategic board of the Medical Research Counsel. He has published numerous articles in magazines of high importance in topics such as primary attention, Health Systems research and the relationship between climate change and health.

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School of Health and Population Sciences College of Medical and Dental Sciences, University of Birmingham
Professor of Public Health Ethics and Head of MESH (Medicine, Ethics, Society and History), University of Birmingham, UK. His background is in philosophy, but he has specialized in teaching ethics to health care professionals and medical students. His main research interests are in public health ethics (particularly vaccinations and issues related to lifestyle choices) and the use of empirical evidence in moral arguments (particularly in relation to problems in gaining informed consent in clinical trials). He is joint Editor-in-Chief of the journal Public Health Ethics and joint coordinator of the International Association of Bioethics' Public Health Ethics Network (InterPHEN). He has raised over 1.5 million pounds in grant income and been

involved in research projects funded by the CDC, WHO, European Union and the Public Health Agency of Canada on a range of issues related to public health ethics. He has published over seventy papers and is editor and co-editor of five collections of original papers mainly on topics in public health ethics, including Dawson, A. (ed.) *Public Health Ethics: Key Concepts and Issues in Policy and Practice*, Cambridge University Press (2011).

Carlos María Romeo Casabona

University of Deusto and University of País Vasco

Criminal Law Professor and Director of the Cátedra Interuniversitaria de Derecho y Genoma Humano, Universidad de Deusto y Universidad del País Vasco. He is a PhD in Law and Medicine and has a Superior Diploma in Criminal Science. He has served as a Substitute Judge for the Territorial Hearing in Zaragoza and as Dean of the Law School of the Universidad de la Laguna. He is an active member of the Bioethics Committee in Spain and of the Bioethics Committee of the European Council, as well as of the Ethics Committee of HUGO and outside advisor of the European Council's group of experts in dangerous criminals.

Carlos Alonso Bedate

Molecular Biology Centre, Autonomous University of Madrid

He graduated in Philosophy from the Pontifical Faculty of the University of Alcalá de Henares and Theology from the Pontifical Faculty of the University of Granada. Master in Genetics from the University of California; degree in Biology from the University of Granada; Doctor of Science from the University of Nijmegen and Granada; Linked Research Professor of CSIC-UAM, Molecular Biology Center at Autonomous University of Madrid. He has participated in fourteen national calls in three EU projects and projects in 21 anthologies, directed 22 doctoral theses and 200 scientific papers indexed. Monitor International malaria vaccine trial (Tanzania). Ethical Adviser EU projects, and Vocal of CDBI (European Council).

Carlos Viesca Treviño
Department of History and Philosophy of Medicine
of the National Autonomous University of Mexico
Carlos Viesca has encouraged numerous generations of students who have formed a medical practice with great human sense and has taken the path of an articulated knowledge of their area with other branches of knowledge, such as Anthropology, Bioethics, History and Philosophy. Viesca is a medical professional whose interest has been, always in a return to the roots, the Nahuatl past, because he understood the importance of the indigenous world, studying their way of treating diseases, medications, herbal his expertise in the human body, their sufferings and their concepts of health.

With over thirty years of professional work, which has been from assistant professor to full time professor Dr. Viesca has worked extensively in the creation of the bioethics course, which is taught in the Master and PhD program of Medicine, Dentistry and Health, at the faculties of Medicine and Science at UNAM. He received the 2004 National Award for University Teaching in Natural Sciences.

Christine Grady
The Presidential Commission for the Study of Bioethical Issues
Chief of the Department of Bioethics at the National Institutes of Health Clinical Center. She also serves as the Head of the Department's Section on Human Subjects Research. Her research focuses on research subject recruitment, incentives, vulnerability, and international research ethics. She is also a senior research fellow at the Kennedy Institute of Ethics and was elected as a Fellow at both the American Academy of Nursing and the Hastings Center. Dr. Grady is a member of the Presidential Commission for the Study of Bioethical Issues.

She has previously served as a consultant to UNAIDS and the Pan American Health Organization and as a staff member to the President's Commission on HIV Infection. Dr. Grady has authored

more than a hundred papers in bioethics, HIV disease, and nursing, and has authored or edited several books. She graduated with a BS in Nursing and Biology from Georgetown University, a MSN in Community Health Nursing from Boston College, and a PhD in philosophy from Georgetown.

David Hunter

School of Medicine, Flinders University, New Zealand

In 2013, David Hunter joined Flinders University as the Associate Professor of Medical Ethics in the School of Medicine. His background are in philosophy, concentrating on political philosophy and ethics, both theoretical and applied, mainly in the context of medical practice, research ethics and other professional practices. He spent the previous eight years in the UK, and before that was based in New Zealand. In 2011-13 he worked at the Philosophy Department of the University of Birmingham. Between 2008 and 2011 he was at the Centre for Professional Ethics at Keele University; in 2005-08 at the School of Biomedical Sciences at the University of Ulster in Northern Ireland; in 2004-05 at the School of History, Philosophy and Politics, Massey University, and from 2000 till 2004 tutored in philosophy at the University of Auckland, New Zealand.

David Koepsell

National Bioethics Commission of Mexico

David Koepsell earned his PhD in Philosophy and Law Degree from the University at Buffalo, NY, USA. He has since practiced for eight years as an attorney, taught at the Buffalo Law school, and also taught philosophy, ethics, legal writing, law and technology, bioethics, and numerous other related subjects, focusing in particular on issues related to research ethics. He is currently an adjunct Professor in the UB department of Learning and Instruction for the online, Science and the Public Masters program. In 2008 he joined the faculty at the University of Delft in the Netherlands. He continues as affiliated scholar with the 3TU Ethics Centre in Holland. He has authored and edited seven books, and authored or co-

authored over 50 scientific articles and chapters for books. He has appeared on diverse news media, and in various newspapers. He now lives in Mexico City with his family where he works at CONBIOÉTICA and continues to write and teach in philosophy, including recently as a Visiting Scholar at UNAM, Instituto de Investigaciones Filosóficas.

Eduardo González Pier
Undersecretary of Integration and Development of the Health Sector, Secretary of Health
Dr. Eduardo González Pier is Undersecretary of Integration and Health Sector Development in the Secretary of Health since 1 March 2014. He previously served as CEO of Funsalud; was CFO of Mexican Social Security Institute (IMSS) from September 2009 to January 2013 where he was responsible for budget policies, risk assessment, treasury operations and overall supervision of the financial management of the IMSS. From 2001 to 2008, Dr. González Pier served as Head of the Economic Analysis Unit of the Secretary of Health, where he was responsible for developing a National Health Program 2001-2006. He also participated in the formulation and implementation of various financial reform, including the introduction of Seguro Popular. Dr. González Pier has a BA in Economics and Mathematics at Washington and Lee University in Virginia and earned Master's and a PhD in Economics from the University of Chicago.

Eduardo Matos Moctezuma
National School of Anthropology and History
He was born in Mexico City in 1940. He has a degree in Archaeology from the National Anthropology and History School, as well as his Master and PhD in anthropologic sciences at the UNAM. He has worked in different archeological sites such as Comalcalco, Teotihuacan, Cholula, Tula, Tlatelolco, Tenochtitlan main temple, among others. His publications are more than 500 articles, reviews, catalogues, guides, biographies and books.

Evandro Agazzi
Metropolitan Autonomus University Mexico
Completed his studies in Philosophy at the Catholic University of Milan and in Physics at the State University of the same city. He then did postgraduate studies and research at the Universities of Oxford, Marburg and Münster. He occupied several teaching positions: at the University of Genoa, at the Higher Normal School of Pisa, at the Catholic University of Milan before and after becoming full professor of Philosophy of Science at the University of Genoa (1970). He also holds the chair of Philosophical Anthropology, Philosophy of Nature and Philosophy of Science at the University of Fribourg in Switzerland, and taught as a visiting professor at the Universities of Düsseldorf, Berne, Pittsburgh, Stanford, and Geneva, as well as at other universities for shorter tenures. At present he is Professor Emeritus of the Universities of Fribourg and of Genoa. In 2009 he moved to Mexico, where he has been Professor at the UAM/Cuajimalpa and Universidad Panamericana.

Gilbert Hottois
Université Libre de Bruxelles
Gilbert Hottois teaches contemporary philosophy at the University of Brussels (Belgium); member of the Royal Academy of Belgium and the International Institute of Philosophy, he has been visiting professor in several universities in America, Africa and Europe. From *L'inflation du langage dans la philosophie contemporaine* (1979) to *Philosophies des sciences, philosophies des techniques* (2004) or *Qu'est-ce que la bioéthique* (2004). Hottois has been member of several ethics committees, such as the European Group for Ethics of Science and New Technologies (to the European Commission) and the Advisory Committee on Bioethics of Belgium. He is currently working on a book about transhumanism.

Graeme Laurie
School of Law, University of Edinburgh
Graeme Laurie is Professor of Medical Jurisprudence at the University of Edinburgh and Founding Director of the JK Mason Institute for Medicine, Life Sciences and the Law.

Graeme Laurie previously held the role of PI and Director of the Arts and Humanities Research Council (AHRC) Research Centre for Studies in Intellectual Property and Technology Law (also known as SCRIPT) from 2007-2011, until he took up the position of Director of Research in the School of Law (2011-2014).

Graeme Laurie was the Chair of the permanent UK Biobank Ethics and Governance Council from 2006-2010 and Chair of the Privacy Advisory Committee in Scotland from 2005-2013. He is currently a member of several external professional and policy bodies including the Nuffield Council on Bioethics. Most recently he has joined the Canadian Academies' Expert Panel on Timely Access to Health and Social Data for Health Research and Health System Innovation since 2014.

Hans van Delden
The Julius Center for Health Sciences of the Medical School, Utrecht University
Is full professor of medical ethics at the Julius Center for Health Sciences of the Utrecht University medical school, and has worked ever since as a house officer at an intensive care ward; he is highly interested in medical ethics. He wrote a thesis on the medical and ethical aspects of the Do Not Resuscitate orders. Moreover, he was one of the principal researchers of the study of medical decisions concerning the end of life for the Remmelink committee. After his education as a nursing home physician he has worked in several nursing homes for fifteen years (until May 2011). His special fields of interest are: research ethics, moral problems at the end of life and moral problems in the care for the elderly. He is currently the president of the Council for International Organizations of Medical Sciences

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Inez de Beaufort
Department of Medical Ethics and Philosophy of Medicine, the Erasmus Medical Centre
Health care ethics professor and head of the department of medical ethics and philosophy of medicine at the Erasmus Medical Centre in Rotterdam, the Netherlands, since 1991. She has studied

theology at the University in Utrecht and written a PhD on human research at the University of Groningen (*cum laude* 1985).

She has published on different subjects in medical ethics, e.g. human research, reproductive technologies, personal responsibility for health, ethics and beauty, medical ethics in fiction (films and novels), the elderly (euthanasia and dementia) and public health issues.Her present research themes are ethics and obesity, medical ethics in literature and films, among others. She has been a member of many ethics committees of hospitals and many national committees, such as the National Council for Health Care, and the Dutch National Committee for Ethics and Medical Research.

She is among others an Honorary member of the Dutch Health Council, also member of the Board of the International Association of Bioethics. She has served two terms in the EGE.

Florencia Luna

Latin American University of Social Sciences (FLACSO)

Principal Researcher at CONICET (National Scientific and Technological Research Council), Argentina. Director of the Program of bioethics at FLACSO (Latin American University of Social Sciences) President of the International Association of Bioethics (IAB) (2003-2005). She has won the Guggenheim Foundation Fellow (2006), is Expert for the World Health Organization (WHO) and member of the Scientific and Advisory Committee (STAC) of the Department of Tropical Diseases Research (TDR) from WHO (2011-2014), member of the Scientific Committee of Brocher Foundation since 2014. Presently she is working in issues related with research in developing countries and also in stem cell research, infertility and gender from a Latin-American perspective.

Jonathan D. Moreno

University of Pennsylvania

Jonathan D. Moreno is a philosopher and historian. As the David and Lyn Silfen University Professor at the University of Pennsylvania, Moreno is one of fourteen Penn Integrates Knowledge professors. At Penn he is also Professor of Medical Ethics and Health Policy, of

History and Sociology of Science, and of Philosophy. Among his books are *The Body Politic*, which was named a Best Book of 2011 by Kirkus Reviews, *Mind Wars* (2012), and *Undue Risk* (2000). His next book, *Impromptu Man: J.L. Moreno and the Origins of Psychodrama, Encounterculture, and the Social Network*, will be published in 2014. Moreno holds a Ph.D. from Washington University in St. Louis, was an Andrew W. Mellon post-doctoral fellow, was awarded an honorary doctorate by Hofstra University, and is a recipient of the Benjamin Rush Medal from the College of William and Mary Law School and the Dr. Jean Mayer Award for Global Citizenship from Tufts University.

John Harris

Institute for Science, Ethics and Innovation (ISEI)
at The University of Manchester

John Harris is Director of The Institute for Science, Ethics and Innovation and of the Wellcome Strategic Programme in The Human Body, its Scope Limits and Future, School of Law, University of Manchester, where he is Lord Alliance Professor of Bioethics.

In September 2006 *The Independent* included John Harris in The Good List, purportedly a list of the fifty men and women who make our world a better place. On 6th September 2008 John Harris featured in *The Times Lifestyle 50*: The top fifty people who influence the way we eat, exercise and think about ourselves. *The Times* citation noted his book *Enhancing Evolution is hugely influential*.

José Ramón Cossío

Justice of the Supreme Court, Mexico

José Ramón Cossío Díaz was born in México city in 1960. He studied law in the University of Colima, where he obtained his bachelor degree in 1984. He earned a Master degree in Constitutional Law and Political Science at the Center for Constitutional Studies in Madrid, from November 1986 to July 1987. He concluded his doctorate in 1988 at the Faculty of Law of the Universidad Complutense in Madrid.

He is currently serving as minister of the Supreme Court of Justice and teaches as well at the Mexican Autonomous Technological Institute. He is also a coeditor of the "Health and Law" section of the *Mexican Medical Gazette*, an article writer for the *Science Magazine of the Mexican Academy of Sciences* and a column writer for *El Universal* newspaper.

José Sarukhán

National Autonomous University of Mexico

José Sarukhán graduated in biology from the National Autonomous University of Mexico (UNAM) in 1964. Obtained a Master's degree in Agricultural Botany at the Postgraduate College (Chapingo) in 1968 and in 1972 obtained a PhD in Ecology from the University of Wales, UK. His main areas of academic interest have been Tropical Ecology Plant Population Ecology, Systems Ecology of both temperate and tropical ecosystems and Darwinian Biology. He was the principal promoter of the main ecological research group in Mexico. He has received Honorary Doctorates from 10 Mexican and Foreign Universities. On October 27, 2011 he received the Gold Congressional Medal to the civil merit. "Enrique Neri" and the Queen Beatrix of the Netherlands Award to him the Order Orange Nassau.

Juan Ramón de la Fuente

Former chancellor of the National Autonomous University of Mexico

Juan Ramón de la Fuente Ramírez is a Mexican psychiatrist, academician and politician who served as Secretary of Health in the cabinet of President Ernesto Zedillo (1994–1999) and as rector of the National Autonomous University of Mexico (UNAM) from 1999 to 2007. He is currently Professor at UNAM and Chairs the Board of the Aspen Institute Mexico. He has written over two hundred papers and fourteen books, and has received numerous awards and honorary degrees such as the Distinguished Alumnus Award from the Mayo Clinic, the Presidential Award for Excellence of the University of Texas and a Doctorate on Humane Letters from Arizona State University, amongst many others. He also received

from former President Vicente Fox the National Prize for Arts and Sciences (Mexico).

Juliana González
Research Seminar on Ethics and Bioethics,
National Autonomous University of Mexico
Juliana González is a PhD in Philosophy at UNAM. Professor Emeritus of Letters and Philosophy Faculty, as well as a researcher Emeritus of the National System of Researchers. She is a fellow of the "Institut International de Philosophie." Juliana González is the author of 22 books, seven of which she is the main author, and for more than 160 specialized articles. She has been distinguished with the National Arts and Science Award of Philosophy, Doctor Honoris Causa in the UNAM, "Universidad Nacional" Award for her research in humanities, among other distinctions.

Julio Frenk Mora
Harvard School of Public Health
Since January 2009, Dr. Julio Frenk is Dean of the Faculty at the Harvard School of Public Health and T and G Angelopoulos Professor of Public Health and International Development. Dr. Frenk served as the Minister of Health of Mexico from 2000 to 2006, where he introduced universal health coverage. He was the founding director of the National Institute of Public Health of Mexico and has also held leadership positions at the Mexican Health Foundation, the World Health Organization, the Bill and Melinda Gates Foundation, and the Carso Health Institute.

María Casado
Bioethics and Law Observatory of the University of Barcelona
Full Professor at the University of Barcelona (Area of Legal, Moral and Political Philosophy) Coordinator of the Consolidated Research Group "Bioethics, Law and Society" of the Generalitat of Catalonia; director and founder of the Master in Bioethics and Law at the University of Barcelona. In November 2006 she received the Narcis

Monturiol Medal by the Government of Catalonia because of her contribution to the scientific progress for her pioneering research in bioethics, grounded in respect for internationally recognized Human Rights, and from mainstream pluridisciplinary and secular standpoints.

Maria do Céu Patrão Neves
University of the Azores, Member of the European Parliament
Professor Patrão Neves is full Professor of Ethics at the University of the Azores; Post-doctorate at the Kennedy Institute of Ethics, Georgetown University (Washington, DC); Member of the Board of Directors of the International Association of Bioethics and Coordinator of International Networks; Expert from Global Ethics Observatory, UNESCO; Portuguese Interlocutor for Brazilian Portuguese relations in Bioethics; author of individual and collective works in the field of bioethics. He is a member of the Portuguese National Council of Ethics for the Life Sciences, and of the European Parliament.

Nayha Sethi
School of Law, University of Edinburgh
Nayha graduated with her LLB (Common and Civil Law with French) from Queens University Belfast in 2008, she then obtained her LLM in Law from the University of Edinburgh in 2009. Nayha is currently working as a Research Fellow on the information governance stream of SHIP (Scottish Health Informatics Programme) under the direction of Professor Graeme Laurie. SHIP is a Scotland-wide project funded by the Wellcome Trust. Nayha was appointed Deputy Director of the Mason Institute for Life Sciences, Medicine and the Law in 2012.

Nicholas Agar
School of History, Philosophy, Political Science and International Relations. Victoria University of Wellington, New Zealand
Nicholas Agar is a New Zealand philosopher interested in the ethical implications of new technologies. He has written three books on the ethics of human enhancement, the most recent of which is *Truly*

Human Enhancement: A Philosophical Defense of Limits (MIT Press, 2014). He has a forthcoming book on the dangers of technological progress and how best to avoid them: *The Paradox of Progress: The Technology Bias Exposed* (Oxford University Press, 2014).

Norman Daniels
Harvard School of Public Health
Norman Daniels is Mary B. Saltonstall Professor and Professor of Ethics and Population Health at Harvard School of Public Health. Formerly Goldthwaite Professor, Chair of the Tufts Philosophy Department, and Professor of Medical Ethics at Tufts Medical School, where he taught from 1969 until 2002, he has degrees from Wesleyan (BA Summa, 1964), Balliol College, Oxford (BA, First Honors, 1966), and Harvard (PhD, Plympton Dissertation Prize, 1971). He has written widely about philosophy of science (Thomas Reid's `Inquiry': the Geometry of Visibles and the Case for Realism (1974; Stanford, 1989), ethics, political and social philosophy including Reading Rawls (1975; Stanford, 1989) and medical ethics.

Patrick Johansson
The Institute of Historical Research, National Autonomous University of Mexico
PhD in Literature for the University of Paris (Sorbonne). He is Principal Investigator for the Historic Research Institute, Pre-Hispanic Literature Professor in the Faculty of Philosophy and Literature, both at UNAM, Investigator in the National System of Investigators (SNI), member of the Mexico City Council of *Cronica*, number member of the de Mexican Academy of Language and responding member of the Royal Spanish Academy, he is also an Honorary Member of the Writer´s Association of Indigenous Languages in Mexico. In 2003 and 2004 he obtain the "Chair Miguel León-Portilla." In 2006 the Sorbonne, Paris III, awarded him with the "Chair Alfonso Reyes." Last August, the Jury of the Mexican Committee of Historic Sciences awarded his article "*Miquiztlatzontequiliztli*, Death as Punishment or Redemption of a Crime" as "Best Article of Ancient History" published in 2010.

Peter Kemp
Center for Ethics and Law at the Faculty of Education
at the University of Aarhus
Peter Kemp is a professor emeritus of philosophy at the School of Education, University of Aarhus, Denmark. He is Executive Director of the Centre for Ethics and Law, Copenhagen, Director of the Department of Philosophy of Education at the Danish University of Education, Copenhagen, President of the Federation Internationale des Societés de Philosophie and Member of l'Academie Internationale de Philosophie des Sciences and l'Institut International de Philosophie, in Paris.

Ruth R. Faden
Johns Hopkins Berman Institute of Bioethics
Ruth R. Faden, PhD, MPH is the Philip Franklin Wagley Professor of Biomedical Ethics and founding Director of the Johns Hopkins Berman Institute of Bioethics. Dr. Faden is the author and editor of many books and articles on biomedical ethics and health policy.

In 2011, Dr. Faden was the recipient of Lifetime Achievement Awards from the American Society for Bioethics and Humanities (ASBH) and Public Responsibility in Medicine and Research (PRIMR). Dr. Faden's current research focuses on justice theory and on national and global challenges in learning health care systems, health systems design and priority setting, and access to the benefits of global investments in biomedical research. He also works on ethical challenges in biomedical science and in women's health.

Ruth Macklin
Department of Epidemiology and Population Health,
the Albert Einstein College of Medicine
Ruth Macklin is Professor of Bioethics in the Department of Epidemiology and Population Health at Albert Einstein College of Medicine in the Bronx, New York, USA. She received a BA with

Distinction from Cornell University and a MA and PhD in Philosophy from Case Western Reserve University. She is an elected member of the Institute of Medicine of the National Academies of Science. She was also president of the International Association of Bioethics from 1999-2001, and has served several terms on its Board of Directors. Since 2001 she has co-directed an NIH Fogarty International Center Training Program on Research Ethics, which takes place in Buenos Aires, Argentina.

Simón Kawa Karasik

The National Institutes of Health and High Specialty Regional Hospitals Coordinating Commission

Physician by the National Autonomous University of Mexico; Postdoctoral Fellowship in Human Genetics, The University of Texas Medical Branch (UTMB). Genetics Specialty, Mexican Council on Genetics. Graduate Certificate in Bioethics, Favaloro University, Buenos Aires, Argentina, Graduate Administration and Management Institutions of Health, Center for Research and Teaching in Economics (CIDE) and University of Barcelona.

He has served as Acting Chief Professor, Faculty of Medicine, UNAM, Mexico; Assistant Professor School of Medicine, UTMB, Galveston Texas; Chief, Division of Clinical Research and Director of Research, and Medical Director also at "General Hospital Dr. Manuel Gea González". Dr. Kawa has published 28 scientific articles in medical journals, 4 book chapters and has supervised 14 graduate thesis.

Søren Holm

School of Law–Healthcare Ethics and Law University of Manchester

Søren Holm holds degrees in Medicine, Philosophy and Religious Studies from the University of Copenhagen. A Masters degree in Health Care Ethics and Law from the University of Manchester, and a PhD and a higher Danish doctorate from the University of Copenhagen.

He has been the President of the European Society for the Philosophy of Medicine and Health Care, and is currently the Vice-President of the International Association of Bioethics. He is a former member of the Danish Council of Ethics and of the Nuffield Council on Bioethics

Tom Beauchamp
The Kennedy Institute of Ethics at Georgetown University
Doctor Beauchamp is Professor of Philosophy and Senior Research Scholar, Kennedy Institute of Ethics, Georgetown University. He took graduate degrees from Yale University and The Johns Hopkins University, where he received his PhD in 1970. He then joined the faculty of the Philosophy Department at Georgetown University and in the mid-1970's accepted a joint appointment at the Kennedy Institute of Ethics. In late 1975, he joined the staff of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, where he drafted the bulk of The Belmont Report (1978) for the Commission.

PRESENTATIONS DELIVERED

Presenter	Abstract title	Country
Adame Maria de los Angeles Marina	Bioethical Analysis of Public Policy Designed to Fight Obesity and Malnutrition in Mexico	Mexico
Aguirre Sala Jorge	Bioethics as Transdisciplinary Science	Mexico
Alcorta-Garza Adelina	Medical Empathy in Iberoamerican Physicians-in-training: Similarities and Differences during their Professional Practice at a Teaching Hospital in Spain	Spain
Alonso Castillo Bertha Alicia	Building Ethical Sensitivity from the Subjectivity of Nursing Students and Professors	Mexico
Alonso Castillo María Teresa de Jesús	Moral Stress in Health Care Professionals	Mexico
Alonso Salas Ángel	Donar ¿un problema bioético?	Mexico
Álvarez Hernández Gerardo	Rocky Mountain Spotted Fever in Sonora: An Epidemiological Problem or an Ethical Neglect?	Mexico
Andreassen Tom	Patent on Genetic Information – Discoveries, Inventions, Processes and Products	Norway
Appleby John B	Why it is Ethical to Create Children with Three Genetic Parents using Mitochondrial Replacement Therapies	United Kingdom

Presenter	Abstract title	Country
Arnason Gardar	Balancing Burdens and Benefits in Neuroscientific Research using Non-Human Primates	Germany
Asplund Kjell	Actors and Arguments Against Surrogacy in Swedish Public Debate	Sweden
Aurenque Diana	Deafness as a Form of Health? Theoretical and Ethical Issues Regarding the Holistic Understanding of Health	Germany
Bagheri Alireza	Medical Futility: Is Policy Development an Option?	Iran
Banyuy Tangwa Godfrey	Are Ethics Local or Universal? The Case of Homosexuality in Africa and Elsewhere	Cameroon
Bavnbek Katrine	Regret in Patients with Acute and Chronic Conditions Recruited to Stem Cell Clinical Trials	United Kingdom
Bazalar-Whu Rosa Elvira	Teachers of Religious Education and Practice of Human Values	Peru
Bélisle Pipon Jean-Christophe	Direct-To-Consumer Information: An Insidious Means of Drug Familiarization leading to Therapeutic Misconception	Canada
Bernabe Rosemarie	The Yardstick of the Pharmaceutical Regulation: Which GCP Issues May Also Be Ethical Issues?	Netherlands
Bhan Anant	Ethical aspects of the move towards Universal Health Coverage: focus on LMICs	India
Bigliardi Marta Alicia	Contamination of Food	Argentina
Birchley Giles	Best Interests in Pediatric Intensive Care Decisions - What Can Practical Understandings Tell Us?	United Kingdom

Presenter	Abstract title	Country
Bórquez Polloni Blanca Marcela	Las bibliotecas parlamentarias como nuevos espacios de deliberación y reflexión para la toma de decisiones normativas en el ámbito de la bioética	Chile
Boulanger Renaud F.	Applying a Health Ethics Policy Framework to the Case of Healthcare User Fee Exemption in West Africa	Canada
Brassart Olsen Céline	Obesity prevention and tobacco control: similarities and differences	Denmark
Brassington Iain	Plain Packaging for Cigarettes: Where Public Health Ethics and Research Ethics Meet	United Kingdom
Bredenoord Annelien L.	Defending the Child's Right to an Open Future Concerning Genetic Information	Netherlands
Brena Sesma Ingrid Lilian	¿A quién beneficia el vacío legal alrededor de la maternidad subrogada?	Mexico
Brown Becky	Public Health and the Influence of Incentives	United Kingdom
Bunnik Sweijs Eline	Is There Such a Thing as Personal Utility in Genomic Testing?	Netherlands
Bustos Saldaña Rafael	Cuatro facetas de valoración en ética y metodología en las investigaciones en seres humanos	Mexico
Caballero Velarde María Cristina	Bioethical Dilemmas and Possible Solutions in Pediatric Intensive Care in the Federal District of Mexico	Mexico
Cabrera Laura Yenisa	Legal and Ethical Issues Around Human-animal Chimera Research	Switzerland
Cabrera Cabrera Antonio	Informed Consent Previous to Assisted Reproduction: A National Inquiry	Mexico

Presenter	Abstract title	Country
Cai Zhen	GM Crops Debate in China: From a Confucian Perspective	United States
Camacho Gutiérrez Sergio Francisco	How Can We Demonstrate Iniquity in Distributive Justice in Patients with Spina Bifida?	Mexico
Canchihuamán Rivera Fredy Antonio	Bridging the Gap: Innovative Approaches to Improve the Efficiency of the Ethical Review Process	Peru
Capron Alexander	Data from mobile devices and clinical healthcare decisions: a new paradigm?	United States
Cárdenas-Morales Beatriz Eugenia	The institutional Bioethics in Mexico: Perspectives and Future	Mexico
Cardozo De Martínez Carmen Alicia	Animal Research and the Three Rs, Updates in Legislation in South America	Chile
Carreño Meléndez Jorge	Reproducción asistida y neoparentalidad: Un dilema ético	Mexico
Carrizosa Sandra Lizbeth	Bioethical Issues in the Resolutions of the Inter-American Court of Human Rights	Mexico
Casas Martínez María de la Luz	Conscientious Objection in Latin America and Spain	Mexico
Cervera Vallerjos Mirtha Flor	Problemas éticos y bioéticos apreciados por los estudiantes de Ciencias de la Salud desde el aula a la práctica hospitalaria	Peru
Chakraborty Rhyddhi	Pandemic A H1N1 (2009) Preparedness Efforts, Compliance, and Some Ethical Considerations: A Retrospective Study on Hijli Rural Hospital (RH), Kharagpur I, West	India
Chandrasekharan Subhashini	Genomics, Commercialization and Benefits in Africa	United States

Presenter	Abstract title	Country
Chen Yen-Yuan	Further Deliberating the Differences between Do-Not-Resuscitate and Allow-Natural-Death	Taiwan (Republic of China)
Child Raquel	International Cooperation in HIV/AIDS from a Bioethics Perspective	Chile
Cicero-Oneto Carlo Egysto	Understanding decision-making in the Setting of Mexican Adolescents Who Died of Cancer: Preliminary Results of a Qualitative Research Study	Mexico
Ciruzzi Maria Susana	Descriptive Study on the Opinion of members of the National Criminal and Civil (Family) Courts in Cases of Witholding or Withdrawing Life Sustaining Treatment	Argentina
Clarinval Caroline	Allocating Limited Humanitarian Resources Fairly: An Ethical Framework to Assist Humanitarian Actors in their Decision-making Process	Switzerland
Consejo y Chapela Carolina	Seniors, Vulnerability and Power Relations: Bioethical Conflicts When Giving Up Treatment	Mexico
Contreras García Roberto Ignacio	Aspectos éticos en la paciente con cáncer de mama	Mexico
Contreras Sieck Miguel Ángel	The Rise of Direct-to-Consumer Genomic Tests and its Implications to Science, Society and the Individual in the Developing World. A Case Study in Mexico	Mexico
Cordero Díaz Mary Ana	Teaching Ethical Standards for the Performance of Healthcare Professionals	Mexico
Cornejo Plaza María Isabel	From Kant´s Categorical Imperative to Fritz Jahr´s Bioethical Imperative: Toward an Ethics of Globalization	Chile

Presenter	Abstract title	Country
Coronado-Zarco Irma Alejandra	Neonatal Health in Mexico. Analyzing Challenges from the Perspective of the Vulnerability Principle	Mexico
Crozier Gillian	Bioethics Education for Ecological Researchers	Canada
Daher Michel	Pain Relief is a Human Right	Lebanon
De Hoyos Adalberto	Right to Autonomy: Dilemmas Arising in a Multicultural Society	Mexico
De la Garza Camino María Teresa	Ethical and Political Aspects of Climate Change	Mexico
De Lecuona Ramírez Itziar	How to Promote Integrity in Research Through Bioethics Committees at University Level	Spain
De Los Ríos María Elizabeth	Justicia y escasez: el problema bioético de la distribución de recursos para la salud	Mexico
De Smet Andries	Climate Change and Obligations of Justice	Belgium
De Sousa Maria Sharmila Alina	Perception and Attitudes of Patients, Relatives, Health Professionals and Regulators on Bioethical Issues: The Case Study of the Brazilian Multiple Endocrine Ne	Brazil
De Souza Birchal Telma	The Moral Status of Embryos: The Limits of the Philosophical Approach on Abortion	Brazil
De Vries Martine	Early Medical Treatment of Children with Gender Dysphoria: An Empirical Ethical Study on Arguments of Proponents and Opponents Concerning Early Interventions	Netherlands

Presenter	Abstract title	Country
Dekking Sara Anna Suzan	Strengths and Weaknesses of Guideline Approaches to Safeguard Voluntary Informed Consent of Patients Within a Dependent Relationship	Netherlands
Dhru Kelly A.	Biotechnological Challenges to the Conceptual Foundations of the Right to Life under the Constitution of India	India
Diniz Nilza Maria	Autonomy Principle into a Sounseling Genetics Service	Brazil
Diniz Nilza Maria	Science and Crime: The Impacts of Bioanthropological Research in Law and in Contemporary Society	Brazil
De Castro Leonardo Doloroso	Determining Validity of Consent Given by Organ Vendors for Transplantation: The Significance of Regret in Output-oriented Assessment	Singapore
Dongosolo Kamalo Patrick	Compensation For Research-Related Injuries – Whither Africa: The Contributory Collaborative Responsibility Approach – A Solution Based On The Traditional	Malawi
Drewniak Daniel	Does Migration Lead to Unjustified Disparities in Health Care? A Factorial Survey among Physicians in Switzerland	Switzerland
Dunn Michael	Voluntariness Is Not a Component of Valid Consent	United Kingdom
Dupras Charles	Gender-dependent Participation in Cardiovascular Genetic Research: An analysis of Consent Forms Reveals Participant Categories	Canada

Presenter	Abstract title	Country
Edwards Patiño Claudia Teresa	Responsabilidad ética hacia los animales de compañía en situación de abandono	Mexico
Edwards Tierney Kyle	A Concept of 'Legitimate Coercion' for the Regulation of Access to Emerging Biotechnologies	United Kingdom
Escobar Lopez Maria Teresa	Perceptions of Informed Consent by Patients from Four Areas of Health Care in Bogota, Colombia 2013	Colombia
Escobar Triana Jaime Alberto	The Role of Bioethics in the Resolution of Ethics Environmental Conflicts	Colombia
Feinholz Dafna	Twenty Years of Bioethics in UNESCO: What Is the Perspective for the Coming Years?	France
Fernández Rivas Plata Gisela Isabel	The Mission of an Ethics Committee Apropos Social Studies: The Experience of the Ethics Committee for the Research on Human Beings and Animals	Peru
Fernando Anoja	Developing Ethical Guidelines for Nanotechnology in Sri Lanka	Sri Lanka
Fetherstonhaugh Deirdre	Hanging on to Some Autonomy in Decision-making in Dementia – How Do People with Dementia and their Carers Do It?	Australia
Fitzgerald Chloë	Implicit Bias in Health Care Professionals: A Systematic Review	Switzerland
Flores Muñoz María Antonieta	Bioethical Issues on the Possibility of Fetal Pain	Mexico
Focquaert Farah	Mandatory Neurotechnological Interventions: Ethical issues	Belgium
Fossheim Hallvard Johannes	Population Studies and the Ethics of Representativeness	Norway

Presenter	Abstract title	Country
Franco Espejel Martha	The Reality in Bioethics	Mexico
Friedrich Daniel	Posteriorizing Marginally Beneficial Treatments – Practical Considerations	Germany
Fuentes Valdivieso Rocío	Bioética y asedio grupal (mobbing) en el trabajo	Mexico
Fuentes Valdivieso Alma Rosa	Bioética, multiculturalidad y cáncer en mujeres zapotecas del Istmo de Tehuantepec	Mexico
Galdino Cardin Valeria Silva	The Achievement of the Parental Project by Plural Families through the Use of Assisted Human Reproduction	Brazil
Galvagni Lucia	Narratives of Health and Disease, Illness and Care	Italy
Gamboa-Bernal Gilberto Alfonso	Quality of Life Related to Health: Equivocal Concept in a Globalized World	Colombia
Ganguly Barna	Newer Practice of Informed Consent Process in India	India
Garzón Díaz Fabio Alberto	Enseñanza-aprendizaje de la bioética basada en problemas	Colombia
Gomes Da Rocha Jailson José	Between the Bioethical Imperative and Land Ethics: The Contributions of Fritz Jahr and Aldo Leopold for the Consolidation of Bioethical Thought	Brazil
González Cifuentes Nadia Lorena	Vector Borne Diseases and Community Based Participatory Research in Colombia: Empowerment to Establish Sustainable Solutions	Belgium

Presenter	Abstract title	Country
González Garza Francisco Xavier	Religion as Bioethical Element that Influences Hospital's Decision-making	Mexico
González Moreno Edith	Medically Assisted Death. National Realities/ International Topics	Mexico
Guerra Martínez Yolanda	Biopolitics of Euthanasia in Colombia	Colombia
Guilhem Dirce Bellezi	Bioethical Aspects of Intra-familiar Relationship in the Context of Home Care	Brazil
Guilhem Matos Luciana	Ethical Requirements in Research Involving Children Affected by Acute Lymphoid Leukemia	Brazil
Gun Mukadder	Is This Real Promise or Real Dilemma? An Ethical Evaluation of Human Embriyonic Stem Cells as a Therapetic Agent	Turkey
Habets Michelle	The Ethical Experiences of Stakeholders in Stem Cell Research	Netherlands
Harmon Shawn	Solidarity in Brain Banking: a Guiding Value for a Public Good?	United Kingdom
Hens Kristien	Epigenetics, Maternal Responsibility and Neurological Development	Netherlands
Herazo Acevedo Edwin	Stigma, Mental Health and Peace Process in Colombia	Colombia
Higuera Olivo Ana Lilia	Reflexiones bioéticas sobre la condición de identidad en pacientes con Trastorno de Diferenciación Sexual (TDS)	Mexico
Hilhorst Medard	Cultivating Integrity: Some Experiences and Obstacles in Ethics Teaching	Netherlands
Ho Anita	Not a Lone(ly) Process: Healthcare Decision Making as a Relational Process	Canada

Presenter	Abstract title	Country
Ho Calvin Wai-Loon	Juridification and Regulationism in Human Pluripotent Stem Cell Research: The Re-Emergence of the State	Singapore
Holm Søren	Should There Be a Right to 'Absenteeism' for Health Care Workers?	United Kingdom
Horn Ruth	"I Don't Need My Patients' Opinion to Withdraw Treatment": Patient Preferences at the End-of-life and Physician Attitudes Towards Advance Directives in England	United Kingdom
Hübel Sylvia	Parental Autonomy and Choice in the Context of Prenatal Diagnosis. Views and Attitudes of Healthcare Professionals and Prospective Parents	Belgium
Hübel Sylvia	Women's Ethical Dilemmas at the intersection of Labour Migration and Care Drain	Belgium
Hunter David	Direct to the Consumer Nocebo Effects - the Ethics of Pharma Advertising & Informing	Australia
Ismaili Mhamdi Hafez	Sen's capabilities approach as an ethical framework for nudging	Netherlands
Jiménez Naranjo Lorena del C.	Análisis bioético del uso de presas vivas en depredadores confinados en zoológicos	Mexico
Jongsma Bosman Karin Rolanda	Morally Relevant Differences in Vulnerable Groups of Research Subjects	Netherlands
Karpin Isabel	Intergenerational Harm: Do We Have an Obligation to Protect the Health of Future Persons?	Australia

Presenter	Abstract title	Country
Kasule Omar Hasan	Bioethicist's Proactive Engagement in Clinical Rounds and Consultations, Hospital Risk Management and Quality Programs: Experiences of the King Fahd Medical City	Saudi Arabia
Katz Michael	To be or Not to be Involved in Medical Decisions Concerning Relatives	Israel
Kelley Maureen	Empowering Children and Caregivers in Pediatric HIV Disclosure: Insights from Kenya	United States
Kenny Belinda	When Eating and Drinking May be Harmful: Perspectives of Patients and Speech Pathologists	Australia
Kirby Jeffrey	Introducing an E2 (Evaluation & Enhancement) Social Accountability Framework for Medical Schools	Canada
Koepsell David	Principals and Principles: Utility, Duties, and Justice in the H5N1 case	Netherlands
Komparic Ana	The Ethics of Introducing GMOs into sub-Saharan Africa: Saharan African Theory of Ubuntu	Canada
Kong Camillia	Which Autonomy? Supportive Decision-Making in Mental Capacity Law and Philosophy	United Kingdom
Koo Young-Mo	An Analysis of Transfer Process of Stored Human Biological Materials to Bio-repositories:	Korea, Republic of (South Korea)
Kumar Rekha	Perceived Benefits and Barriers of Telemedicine in Botswana: A Preliminary Study of Two Referral Hospitals in Botswana	Botswana
Kuppuswamy Chamu	United Nations Declaration on Human Cloning: 10 Years On	United Kingdom

Presenter	Abstract title	Country
Lagos Karin	Impacto de una metodología activa de enseñanza realizada por monitores adultos mayores	Chile
Lederman Zohar	Attitudes of Healthcare Providers Towards Family Presence during Resuscitation: A Cross-Cultural Comparison	Singapore
Ledesma Fernanda María	El mejor interés en Pediatría	Argentina
Leyton Fabiola	Factory Farming , Global Bioethics and Public Health: New Challenges	Spain
Leyton Fabiola	Reflexiones sociales y bioéticas sobre el movimiento de los derechos animales en Latinoamérica	Spain
Lin Yun-Hsien Diana	Consensus Conferences on Gestational Surrogacy: Autonomy, Procreative Rights and Gender	Taiwan (Republic of China)
Lopes Godoi Laís	Beyond Dichotomies: An Informational Approach to Personal Identities	Brazil
Lopes Godoi Laís	Gender-neutral Parenting: Towards New Possibilities of Open Futures	Brazil
Luco Lorna	Review of Instruments for Assessing Decision-Making Capacity in Senior Adults: A Legitimate Need	Chile
Macpherson Cheryl	Bioethics and Health in the Changing Caribbean Environment	Grenada
Malicki Mario	Editorial Police What You Say? Analysis of Duplicate Publications in PubMed	Croatia
Malpas Phillipa J.	Physician-assisted Dying in New Zealand: What Do Older Persons Think and Why?	New Zealand

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Mangadan Konath Nabeel	Ontological Exploration of Vulnerability using a Conceptual Model beyond its Epistemological Limitations	India
Marshall Felice	Fit for the Future: Misdiagnosing the Need for Moral Enhancement	New Zealand
Marshall Jennifer A.	The Moral Discourse of Uncertainty in Clinical Genomics	Canada
Martin Dominique	Dialling International for Consent to Deceased Donation – Ethical Hazards in Family Consultation	Australia
Mastroleo Ignacio Damián	Post-trial Obligations towards Research Participants: a Critical Assessment of the Declaration of Helsinki 2013	Argentina
Mayorga Madrigal Cuauhtémoc	Factors that Inhibit and Factors Favoring the Exercise of Autonomy in Health Sector	Mexico
McDougall Rosalind	Are Parents Ethically Entitled to Refuse Fertility Preservation Procedures for their Child with Cancer?	Australia
Ménard Jean Frédéric	Grounded Normative Theory as a Methodology for Empirical Law and Ethics	United Kingdom
Mercado Velázquez Gabriel	LET en Psicoterapia	Mexico
Millum Joseph	Valuing Stillbirths	United States
Moazam Farhat	Reading Caplan in Karachi	Pakistan
Molina Santiago José	The Social and Ethical Consequences of Ambiguous Definitions of 'Population' in Community Resource Projects: The case of the 1000 Genomes Project	United States

Presenter	Abstract title	Country
Mondragón Liliana	Pertinencia de los componentes éticos de la ciencia biomédica para la investigación social en salud mental	Mexico
Montañez Mendoza Ana María	The Initial Experience of Interactive Tutorials in the Diffusion of Bioethics at the Medical College of Peru in 2013	Peru
Morris Baraka Malaki	Ethical Presentation of AIDS in Africa	Tanzania
Mulvaney-Day Norah	Agency, Identity and Behavior Change: Shifting from an Individual to a Relational Model	United States
Munthe Christian	A Framing Problem for Public Health Ethics: Addressing the basic Issue of Scope	Sweden
Muñoz Del Carpio Toia Agueda	Aspectos éticos de la investigación sobre violencia de género y violencia familiar	Peru
Muñoz Del Carpio Toia Agueda	Participating Democracy in Latin America: Ethical Aspects of Indigenous / Native Communities´ Research	Peru
Nacea Diana	The New EU Standards for Aesthetic Surgery Services	Denmark
Nasser Cury Carolina Maria	The Legal Status of Animals in Brazil	Brazil
Nava-Diosdado Moisés Rodrigo	Gathering up the Loose Ends of Dispute Settlement in Clinical Practice	Mexico
Navarro Silvia	Acces to Legal-Bioethics Data in Networks	Spain
Navarro Silvia	Cuestiones bioéticas pendientes en el ámbito sanitario: ¿objeción de conciencia o desobediencia civil?	Spain

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Newson Ainsley	Using New Genetic Sequencing Methods in Children: Should Context Matter?	Australia
Nicholls Stuart G.	A Shared Understanding? Attitudes of Stakeholders to Newborn Screening Consent Practices	Canada
Nicolás Jiménez Pilar	Donación de óvulos humanos. Cuando los cimientos del consentimiento se tambalean	Spain
Nie Jing-Bao	Cross-Cultural and Global Bioethics: The Elements of a Transcultural Approach	New Zeland
Niemansburg Sophie Louise	The Ethics of Sham Interventions in an Era of Emerging Biotechnology	Netherlands
Nuramo Adamu Addissie	Use of Rapid Ethical Assessment to Improve Health Research Informed Consent Processes in a Low-Income	Ethiopia
Oakley Justin	Physician Acquiescence, Medical Virtue, and Evaluative Conditioning in Direct-to-consumer Pharmaceutical Advertising	Australia
O'Connell Karen	Will Neuroscience Become an Apology for Violence? Disability, Law and the Aggressive Legal Subject	Australia
Olivares-Durán Enrique Mario	Dysthanasia and/or Futile Care in the Intensive Care Units of a Specialty Hospital in El Bajío Region, in Mexico	Mexico
Ornelas Duarte Aracely	Interpretation of Article 4.1: Review and Analysis of the Ulterior Practice of States Members of the American Convention on Human Rights	Mexico
Ortiz-Millán Gustavo	Against Pedigree: The Ethics of Artificial Selection in Dogs	Mexico

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Outon de La Garza Santiago	Ethics and Climate Change	Mexico
Paéz Moreno Ricardo	Solidaridad y el derecho a la atención de la salud	Mexico
Palacios González César	Clinical Photography and Social Media	United Kingdom
Pallarés Domínguez Daniel	My Brain Made Me Not Do it: Neurodeterminism and the Negative Sense of Free Will	Spain
Patiño González Ixchel Itza	Justice in Health Decision Making	Mexico
Peeters Wouter	IPAT-ethics: Some Normative Considerations with Respect to Reducing Humanity's Aggregate Environmental Impact	Belgium
Pereira Carvallo Nara	Liberdade, democracia e afetividade às relações familiares: por um modelo aberto de família	Brazil
Pérez Bravo Mauro	Transexualidad: Del derecho a la no-identidad al derecho a la salud	Mexico
Pessini Leo	Dysthanasia – The Futile and/or Useless Medical Treatment in Brazil: From the Anguish of the Decision to the Serenity of the Bioethical Dialogue	Brazil
Piedra-Herrera Daniel	Bioética contracorriente	Cuba
Piekarewicz Sigal Mina	Bioética, aborto y políticas públicas	Mexico
Pineda Hernández Gabriela	Meanings of Menopause. Body, Gender and Experience	Mexico
Porter Gerard	The Globalisation of Clinical Trials: How the Market Shapes Law and Bioethical Discourse	United Kingdom

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Postan Emily Rose	Interpreting the Body: Bioinformation as a Tool of Selfconception	United Kingdom
Pratt Bridget	The Ethics of Priority Setting for Health Systems Research in Developing Countries: Should Global Priorities Drive National Priorities?	United States
Pretorius Blanche	A Lens on Current Documentation of Research Ethics Committees in South Africa Which Guide Ethics Review of Research Involving Children as Participants	South Africa
Pringle John	Real-time Responsiveness and Disaster Research Ethics	United States
Ramírez Barreto Ana Cristina	Bioethics Experts? Criticism, Necessity and Previsions for Our Future IRBs	Mexico
Ramírez García Hugo Saúl	Bioética, derecho e imparcialidad judicial. Análisis crítico a la Sentencia Artavia Murillo y otros vs. Costa Rica	Mexico
Ramos-Kuri Manuel	Toward a Proper Comprehension of the Human Zygote	Mexico
Ravitsky Vardit	In Vitro Fertilisation Users Attitudes toward Postmortem Assisted Reproduction	Canada
Raymundo Marcia Mocellin	Informed Consent Process in Intercultural Contexts	Brazil
Reichardt Jan-Ole	Encouraging Conscientiousness in Risk Associated Areas of (Medical) Research	Germany
Ribeiro Mendes Daniel	Towards New Possibilities of Dignified Personhood: Superseding the Homo Sapiens	Brazil

Presenter	Abstract title	Country
Ribeiro Mendes Daniel	Empatia e altruismo como pressupostos para a implementação de políticas públicas de combate à pobreza: Premissas para discussão da viabilidade ética dos melhoramentos morais	Brazil
Rid Annette	Stratifying Risk in Research Regulation and Oversight	United Kingdom
Rivera Montero Rafael	Proposal for the Analysis of Issues Bioethical Dilemma	Mexico
Rivera Obando María Isabel	Aspectos éticos de la investigación sobre violencia de género y violencia familiar	Chile
Rivero Weber Paulina	Más allá de la compasión	Mexico
Rodríguez Otero Raúl Héctor	Ten Criticism Thesis about Bioethics	Mexico
Rodríguez Sánchez Katya Marion	Bioethics, Donation of Medicines and Disease of Poverty. Analysis of a case of Public Health	Ecuador
Rodríguez-Rodríguez José Gilberto	Bioethics and Interculturality	Mexico
Roduit Johann	The Ideal Human as a Guide to Human Enhancement?	Switzerland
Romeo Malanda Sergio	El diagnóstico genético pre-implantatorio (DGP) sobre embriones en la normativa y en la práctica española	Spain
Rozynska Joanna	Moral Bioenhancement and Virtues	Poland
Ruiz-López Edgar René	Designing the Best Possible Existence: The Non-identity Problem, Genetics and our Duties to Future Generations	Mexico

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Rawlinson Mary C.	On the Necessity of Universals in Bioethics	United States
Saenz Carla	Separate Goals, Converging Priorities: On the Ethics of HIV Treatment as Prevention	United States
Sagols Sales Lizbeth Margarita	Climate Change, Health Problems and Anthropocentrism that Overpopulates	Mexico
Sánchez Barroso José Antonio	Hacia una epistemología de la bioética	Mexico
Santi María Florencia	El debate sobre los daños en investigación en ciencias sociales	Argentina
Santillán Doherty Patricio	¿Es válida la objeción de conciencia en la medicina?	Mexico
Santos Alcántara Manuel Jesús	Fate of Cryopreserved Human Embryos Produced by IVF: New Scientific and Bioethical and Legal Implications	Chile
Schmidt Harald	Is There an Ethical Obligation to Think about One's Health, and If So, Should We Use Rewards or Penalties for Encouragement? The Case of Health Screenings	United States
Schmidt-Felzmann Heike	Competent Research Participants: Vulnerable or Powerful?	Ireland
Schmietow Bettina	On the Ethics of Dynamic Consent	Italy
Scully Jackie Leach	Faithful Bioethical Judgements: Negotiating Personal, Social and Faith Group Norms	United Kingdom
Shamsi Gooshki Ehsan	Bioethics and Islamic Government: Iran Experience	Iran
Sheehan Mark	How Broad is Too Broad? Justifying Models of Consent to Research	United Kingdom
Silva Diego	Kant's Political Philosophy and Its Contribution to Public Health	Canada

Presenter	Abstract title	Country
Smith Maxwell J.	Just What is Just in Public Health Emergency Preparedness and Response? Preliminary Findings from a Qualitative Study of Public Health Policy-maker Perspectives	Canada
Snijdewind Marianne	Evaluation of the End-of-Life Clinic	Netherlands
Stancioli Brunello	Human Enhancement as a Basic Right	Brazil
Stancioli Brunello	Despessoalizando a população da identidade pela falta de reconhecimento	Brazil
Sueiras Altamirano Perla Ximena	Axiology of the Ends of Medicine	Mexico
Tang Jian	The Elephant in the Operating Room: A Qualitative Study on Disclosing Senior Colleague's Medical Errors	China
Tarasco Martha	Vulnerability: Considerations on the Appropriate Use of the Term in Bioethics	Mexico
Terlizzi María Sol	Bioethics and Intellectual Property. Current Debates about Pharmaceutical Patents: The Case of High Cost Medicines (HCM)	Argentina
Tock Rebacca	Accounting for Illness in the Medical Encounter - A Tailored Account of Autonomy	Australia
Tromp Krista	Children in Clinical Drug Research: Why Do They Participate?	Netherlands
Tsai Daniel Fu-Chang	Reflecting on the Ethics and Policy for Transplantation Tourism	India
Van Assche Kristof	The Re-examination of the Council of Europe Biobank Recommendation: Current Status	Belgium

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Van Bodegom Lisa	Incidental Findings through Imaging in Population-based Research: Participant Perspectives	Netherlands
Van De Vathorst Suzanne	The Good Death	Netherlands
Van Der Eijk Yvette	Ethical Considerations for a Tobacco Phase-Out	Singapore
Van Der Graaf Rieke	The Responsiveness Requirement Revisited: Global Attention for Global Health Needs and Priorities	Netherlands
Van Niekerk Anton Albert	Is Biomedical Enhancement a Disenchantment of the World?	South Africa
Vanda Cantón Beatriz	Vulnerabilidad y violencia hacia los animales	Mexico
Vanderhaegen Bert Rene Helene	The Three Most Important Ethical Principles in the Prioritisation Debate	Belgium
Vargas Almaraz Manuel	Ethical Aspects of Gender Violence and Domestic Violence: Peruvian and Mexican Cases	Peru
Vázquez Cardozo Rodolfo Dario	Laicidad y objeción de conciencia	Mexico
Vazquez Valenzuela Marcela Patricia	Neuroethics of Medical Therapy in Attention Deficit Hyperactivity Disorder	Mexico
Vela Staines Jose Arturo	Bonding and its Impact on Public Policy to Decrease Violence \ Applied Bioethics	Mexico
Verges de Lopez Claude	Public Health and Implementation Research in Latin America	Panama
Verweij Marcel	The Immorality of Research Exploiting Unhealthy Living Conditions in a Population	Netherlands
Vilchis Macedo Claudia Jimena	Child Abused Detection by Bioethics Committee	Mexico

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Villa Páez Itzel	Ethical Implications in the Allocation of Organs Targeted the Elderly	Mexico
Villalba-Caloca Jaime	Integral Perspective of a Bioethical Case	Mexico
Villanueva Sáenz Claudia	Qualitative Determination of Care Ethics Elements in Nursing in Institutions in Mexico City	Mexico
Villela Cortés Fabiola	El uso de animales en experimentación	Mexico
Waechter Randall	Estimating the Social Priority of Addressing Violence Against Women	Grenada
Waligora Marcin	Age Threshold and Assent in Paediatric Research	Poland
Warner Alan	Ethical Considerations in Genomic-based Personalized Medicine	Canada
Warren Rachel	What is Parenthood? What is the Moral Scope of Parenthood?	United Kingdom
Washburn Calvo Jimmy Jose	Autonomy: Three Suggestions for More Applications in Costa Rica	Costa Rica
Weingerz Samuel	Bioethical Considerations of Informed Consent or Agreement in Teen Pregnancy	Mexico
Wendler David	Ethical Double Standards: What are They? What Can Be Done About Them?	United States
Wenner Danielle	Unpacking the Social Value of Research-Generated Knowledge	United States
White Karolyn Leslea	Ethical Implications of Research Ethics Review of Social Science Research	Australia
Wiesing Urban	The Latest Version of the Declaration of Helsinki: Changes and Challenges	Germany

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Wilbe Ramsay Karin	Ethical Aspects on Mitochondrial Replacement – Reflections from the Swedish Ethics Council	Sweden
Wild Verina	Migration on Elderly People in Need of Longterm Care and its Ethical Issues	Switzerland
Wild Verina	What is the Role of Cultural Relativism in the Case of Hymen Reconstruction?	Switzerland
Wilkinson Stephen	Exploitation in International Surrogacy Arrangements	United Kingdom
Wrigley Anthony	Genetics, Identifity and Triparenting	United Kingdom
Yacarini Martínez Antero Enrique	The Bioethics in the Biomedical University Teaching	Peru
Yakubu Aminu	The Governance of the Key Health Financing Mechanisms in Nigeria for Achieving Universal Health Coverage: A Case-study of Ethics in the Health System: A Brief	Nigeria
Yudin Boris	Individual Human Existence in the Light of Bioethics	Russian Federation
Yuehong Han	Does Human dignity Have Nothing to Do With the Physical Body?	China
Zhang Haihong	Why Privacy Is or Is Not so Important in Human Subject Protection: A Comparative Study Between Chinese and American Patient Subjects	China

POSTER PRESENTATIONS DELIVERED

Presenter	Poster title	Country
Aguas Pereira Cintia	Privacy and Trust in Biobanks for Research – The Portuguese Context	Portugal
Aizawa Kuniko	Designing a Public System for the Research Ethics Consultation Service in Japan	Japan
Alonso Bedate Carlos	Re-Identification Risk from Genome Wide Association Studies (GWAS)	Spain
Alonso Bedate Carlos	Spanish Regulatory Approach for Biobanking	Spain
Álvarez Díaz Jorge Alberto	Neuroethics and Neurosciences in (for?) Developing Countries	Mexico
Amorim Costa Cristiane Maria	Building a List of the Basic Functionings for Transgender People	Brazil
Anguiano Serrano Sandra Angélica	Differences in Perception of the Acquisition of Ethical Values in College Students in a Mexican Campus	Mexico
Bellezi Guilhem Dirce	Memory Project: History, Research and Ethics	Brazil
Bórquez Polloni Blanca Marcela	From Object to Subject: The Adolescent as Actor of his Health Care	Spain
Calderón Jorge Alberto	Moral Education About the Students of Odontology in FESI UNAM and their Conduct Code	Mexico

Presenter	Poster title	Country
Cañete Roberto	Scientific Research: Institutional and Social Responsibility	Cuba
Caputo Dorta Daniela	Discussion About Ethics of the Placebo Use in Clinical Trials for Chronic Pain	Brazil
Choi Sungkyoung	Experts' Legal Knowledge on Personalized and Genomic Medicine and its Ethical Implication in South Korea	Korea, Republic of (South Korea)
Cristina Cantisani Gabriela	Scientific Integrity in Brazil: Analysis of the Scientific Literature	Brazil
Ersoy Mesut	The Patient\'s Physically Protection of Privacy and the Responsibility of Physicians: An Assessment Reflected on the Media Through Examples	Turkey
Estevao Rosane	The Contribution of Movies to Bioethical Reflections	Brazil
Figueroa Perea Juan Guillermo	Ethical Reflections on The Social Commitment of University Knowledge	Mexico
Flores Sandra Inés	Complaints About Health Services	Peru
Galdino Cardín Valeria Silva	The Reality of Transsexuals in Brazil	Brazil
García Scougall José Pedro	Does Bioethics Need or Not Accept a Fundation of Human Rights?	Mexico
García Solís Eduardo	Implementing Normative and Regulative Documents For Ethical Control in Research at Campeche, Mexico	Mexico

Presenter	Poster title	Country
Gladwyn Mwinga Alwyn	Community Advisory Boards: The Need to Expand their Involvement as Advisors to True Partners in the Design of Research Studies	Zambia
González Garza Francisco Xavier	Ethical and Bioethical Issues in Football	Mexico
González Ramírez Gloria Inés	University Education in Bioethics	Colombia
Grether Patricia	End of Life Decisions in the Perinatal Medical Care	Mexico
Guevara Jovita	Ethical Review of Research Conducted in Peruvian Universities	Peru
Guevara López Uria Medardo	Cross-Functional Analysis of Ethical Dilemmas in Palliative Care	Mexico
Haidar Hazar	Non-Invasive Prenatal Testing: An "Option" to Test or a "Pressure" to Test?	Canada
Jafarey Mustafa Aamir	Facing Facebook: Ethical Challenges for Medical Professionals	Pakistan
Jongsma Karin Rolanda	Advance Research Directives in Dementia Research: What Does It Solve?	Netherlands
Joury Sophie	Fining The Flab: Should Weight Loss Be Mandatory for the Obese?	United Kingdom
Joyce Richard	Normalicy and Normativity	New Zealand
Kurt Engin	Determination The Success of Informed Consent Before Surgery that Patients Undergoing Surgical Operation? An Example of a Training Hospital	Turkey

Presenter	Poster title	Country
Lawrence David	Captain America: Technoprogressive Avenger? The Problem of the Superhero For the Bioconservative Position on Enhancement	United Kingdom
Lizárraga López Sandra Luz	Identifying Dilemmas in Pediatric Cancer Patients and Their Admission to Intensive Care Unit	Mexico
Loria Argaiz Agustín	A Bioethics Committee in a Private Hospital, 5 Years	Mexico
Louk Kristi	Biobank Research and (Potential) Duties of Researchers'. On Beneficence, Research-Care Distinction and Therapeutic Misconception in Era of Incidental Findings	Estonia
Luengas Aguirre Maria Isabel de Fatima	Construction of Citizenship in Health Care Space: Between Frustration and Indiference	Mexico
Magalhaes Gontijo Pollyana	Ethics in Scientific Practice of a Biobank	Brazil
Marceles Guerrero Víctor	Organization and Functioning of the National Bioethics Council of Colombia Since a Global Vision	Colombia
Marimon Díaz Yuri Jesús	Ethical Analysis of Health Services in Patients With Rare Diseases in Ecuador	Ecuador
Medina Ortiz Sofía Guadalupe	Effect of Bioethics Program in Developing Moral Judgment of Nursing	Mexico
Mejía Estrada Adriana	Bioethics in Physician - Patient Relationship and Development of the Medical Record	Mexico

Presenter	Poster title	Country
Mendoza Olvera María Aurea	Influence of the Emotional Sphere on the Ethical Attitudes in the Health Care Professional	Mexico
Monteon Yareni	Perceptions of Justice in Health Care: A Theoretical and Empirical Analysis	Mexico
Moreira Gricelda Ethel	New Family Configurations	Argentina
Morelos Herrera Paula	Attitudes of Geneticists and Ophthalmologists Regarding Genetic Counseling for Retinoblastoma in Mexico	Mexico
Namal Fatih	Concept of What Constitutes a Difficult Ethical Problems in Military Medicine: Malingering	Turkey
Olvera Arellano Ana Guadalupe	The Human Genome: An Open Door to our Intimacy?	Mexico
Pacheco Gómez Alejandro	Bioethics In Mexican Law	Mexico
Palma Gloria Inés	The Network of Human Research Ethics Committees in Cali, Colombia: Protecting Human Subjects	Colombia
Paredes-Salazar Betty Carmen	Under Aged, Underprivileged snd Pregnant, Two Cases From Peru	Peru
Pérez Cavazos Berenice Lizeth	Opinion of University Students on Management of Genetic Information	Mexico
Piasecki Jan	Individual Interests and Research With No Prospect Benefit Involving Incompetent Subjects	Poland
Pichardo García Luz María	Development of an Instrument for Early Detection of Psychopath Behavior, Based on Hare's Test	Mexico

Presenter	Poster title	Country
Ponce Arango Amparo	Discrimination that Suffer Mexicans Who Have Epilepsy in the Field of Work	Mexico
Ramírez Soltero Eduardo	Bioethical Issues Considered in Human Research at the University South Center in University of Guadalajara	Mexico
Rodríguez Alanis Martha Marcela	Teenagers Attributes on Sociomoral Reasoning as a Building Process of Bioethical Competences	Mexico
Rodríguez Alanis Martha Marcela	The Socio-Moral Reasoning Traits of Adolescents as a Process of Building Bioethical Skills	Mexico
Rodríguez Gilma	Inequidad en el campo colombiano: un problema de justicia social	Colombia
Rodríguez María Victoria	Violencia contra las mujeres en Colombia: un desconocimiento de su dignidad	Colombia
Ruzario Sithembile	Exploring Research Participants' Perceptions and Comprehension of the Informed Consent Process in a Pre-Exposure Hiv Prevention Study in Zimbabwe: a Case Study	Zimbabwe
Salazar Cruz María De Los Ángeles	Informed Assent in Pediatric Dentistry	Mexico
Sandoval Gutiérrez José Luis	Pulmonary Diseases and Ethics Issues	Mexico
Serdar Yurdakul Eray	Implementation of Assisted Reproductive Techniques in Single Women	Turkey

Presenter	Poster title	Country
Serrano Delgado Valente Moisés	Blood Donors and Healthcare Workers' Perspectives on Notification Process of Permanent Deferral: Preliminary Results	Mexico
Sleem Hany	Post Trial, Poor Patients Continued Access to the Drug Success	Egypt
Tellez Elizabeth	The Use of Animals in Biology Sciences	Mexico
Toader Elena	Conscientious Objection in the Medical Migration Context: Cultural Interference	Romania
Vázquez Arreola Leticia	Effects of Course of Ethics in the Development of Moral Judgment of Nursing Students	Mexico
Villarreal Guerra Pablo	Medical Tourism and Bioethics	Mexico
Yescas Buendia Gabino	Constitutional Responsibility, Individual and Group of Bioethics In the Promotion and Quality Health	Mexico
Zafalon Martins Gerson	Flexibilization of the Norms for Research: The Case of Brazil	Brazil

SYMPOSIA DELIVERED

Towards a global consensus on an ethical framework for medical products of human origin por Towards a Global Consensus on an Ethical Framework for Medical Products of Human Origin

Bouësseau Marie-Charlotte	Switzerland
Capron Alexander	United States
Clarinval Caroline	Switzerland
Dib-Kuri Arturo	Mexico
Luna Florencia	Argentina
Martin Dominique	Australia
Moazam Farhat	Pakistan
Willems Dick	Netherlands

The Ethics of Mitochondrial Replacement Therapy

Appleby John B.	United Kingdom
Bredenoord Annelien L.	Netherlands
Ravitsky Vardit	Canada
Wilkinson Stephen	United Kingdom
Wrigley Anthony	United Kingdom

Towards a Normatively Oriented Empirical Bioethics

Kihlbom Ulrik	Sweden
Lindemann Hilde	United States
Scully Jackie Leach	United Kingdom

The Social Value of Research: Conflicts between Science, Society, and Individuals

Rid Annette	United Kingdom

Shah Seema K	United States
Van Delden Hans	Netherlands
Wendler David	United States
Wertheimer Alan	United States

Methods of bioethics

Árnason Vilhjálmur	Iceland
Dawson Angus	United Kingdom
McMillan John	New Zealand
Selgelid Michael J.	Australia

Control: Duty and Virtue, Nightmare and Fear; Security and the Role of the Ethics Committees. A Latin-American- EU

De Beaufort Inez	Netherlands
Burrows Jaime	Chile
Dratwa Jim	Belgium
O'sullivan Siobhan	Ireland

Diabetes y la pobreza una paradoja de nuestra era, un análisis desde el punto de vista bioético

Chávez Prieto Sara	Mexico
Contreras García Roberto	Mexico
Granillo Saliasis Juan Manuel	Mexico
Martínez Pérez Octavio	Mexico
Rodríguez Rico Matilde	Mexico

Should Bioethicists be Activists: Do We Need a Translational Bioethics?

Brassington Iain	United Kingdom
Hunter David	Australia
Wilson James	United Kingdom

Biobanking in Africa

Gladwyn Mwinga Alwyn	Zambia
Juengst Eric	United States

Moodley Keymanthri	South africa
Staunton Ciara	South africa

Patient Death Seen by the Members of the Committee on Bioethics Hospitable, Hospital of Juarez Mexico

Delgado Ochoa Dolores	Mexico
Domínguez Márquez Octaviano Humberto	Mexico
González Ramírez Julieta Cecilia	Mexico
Hernández Bernal Clara Elena	Mexico
Tejeda Romero Mónica	Mexico

Financial and Other Incentives for Lifestyle: Ethical Issues

Brown Becky	United Kingdom
De Beaufort Inez	Netherlands
Schmidt Harald	Germany
Willems Dick	Netherlands
Whittall Hugh	United Kingdom

Ética en investigación: vulnerabilidad y protección

Cardoso De Martinez Carmen Alicia	Chile
Guilhem Dirce Bellezi	Brazil
Quiroz Malca Estela	Peru
Sáenz Carla	United States

Evidence-Based Research Regulation?

Bhan Anant	India
Hunter David	Australia
Rid Annette	United Kingdom
Schmidt-Felzmann Heike	Ireland
Whitney Simon	United States
Wilson James	United Kingdom

Social Determinants of Health and Research Ethics: Challenges of an EU Funded Research (SDH-NET)

Borde Elis	Brazil
Cash-Gibson Lucinda	Spain

Mamdani Masuma	Tanzania
Martínez Palomo Adolfo	Mexico
Stuckelberger Astrid	Switzerland
Urbina Fuentes Manuel	Mexico

Construction of Knowledge in Bioethics

Campos Campos José Alberto	Mexico
Viesca Treviño Carlos	Mexico

From Bioethics to Bioart: The Question about the Limits

Ballangée Brandon	United States
Dorotinsky Alpersteir Deborah	Mexico
González Valerio María Antonia	Mexico
Karafyllis Nicole Christine	Germany
Lomelí Bravo Sebastián	Mexico
Reichle Ingeborg	Germany

The Islamic Theory and Principles of Ethics within the Global Ethical Diversity

Hasan Kasule Omar	Saudi Arabia

Analysis of the Inter-American Court of Human Rights Ruling on the Case of Artavia Murillo *et al*. ("In Vitro Fertilization") *vs*. Costa Rica

Ramos-Kuri Manuel	Mexico
Sánchez Barroso José Antonio	Mexico
Tarasco Martha	Mexico

Place, Care, and Bioethics

Fanning Joseph	United States
Illes Judit	United States
Lindemann Hilde	United States

Ethics of Translational Stem Cell Research: Moving Pluripotent Stem Cells to the Clinic

Bredenoord Annelien L.	Netherlands

Habets Michelle	Netherlands
Sugarman Jeremy	United States

An Ethical Evolution of Sexuality

Abarca-Garcia César Antonio	Mexico
Oliver-Morales Celia	Mexico
Buzo-Zarzosa Diana	Mexico

Special Session: "El final de la vida y el testamento vital" organized by Universidad Autónoma del Estado de México

González Fabián Elba Margarita	Mexico
Guadarrama Guadarrama Rosalinda	Mexico
Herreros Ruiz Valdepeñas Benjamín	Spain
Márquez Mendoza Octavio	Mexico
Martínez Pérez Sergio Gerardo	Mexico
Palacios García-Cervigón Gregorio Jesús	Spain
Rivera Obando María Isabel	Chile
Veytia López Marcela	Mexico

Etnografía y bioética: la experiencia de un grupo transfuncional

Altamirano Bustamante Nelly F.	Mexico
De Hoyos Adalberto	Mexico
Lizárraga López Sandra Luz	Mexico
Nava Diosdado Moises Rodrigo	Mexico

Ethics of Universal Health Coverage

Ho Calvin Wai-Loon	Singapore
Reis Andreas	Germany
Sáenz Carla	United States
Wikler Daniel	United States

Migrants, Health Care, and Ethical Responsibility

Dwyer James	United States

Wild Verina	Switzerland
Wilson James	United Kingdom

The Tissue/Data Divide: Paradigms, Property & Privacy

Brassington Iain	United Kingdom
Laurie Graeme	United Kingdom
Postan Emily Rose	United Kingdom
Whittall Hugh	United Kingdom
Sethi Nayha	United Kingdom

Integrity in Medical Research: Urgent As It Is

De Beaufort Inez	Netherlands
De Castro Leonardo Doloroso	Singapore
Hilhorst Medard	Netherlands
Holm Søren	United Kingdom
Pinxte Wim	Belgium
Van De Vathor Suzanne	Netherlands

Men and Reproduction: Some Controversies on 'Fathering'

De Beaufort Inez	Netherlands
Ismaili Mhamdi Hafez	Netherlands
Pinxte Wim	Belgium

Ethical Issues in Public Health Surveillance

Reis Andreas	Germany
Saxena Abha	India
Selgelid Michael J.	Australia

Cross-Border Stem Cell Therapies: International Governance and Harmonization

Chan Sarah	United Kingdom
Harris John	United Kingdom
Lisker Ruben	Mexico
Medina Arellano Maria De Jesus	Mexico
Tapia Ricardo	Mexico

Regulation of Research, Efficiency and Internationalization: Does One Size Fit All?

Ho Calvin Wai-Loon	Singapore
Hunter David	Australia
McMillan John	New Zealand
Rid Annette	United Kingdom

Real Time Bioethics: Axiology of Clinical Practice

Altamirano-Bustamante Myriam	Mexico
Altamirano-Bustamante Nelly	Mexico
De Hoyos Adalberto	Mexico
Guevara Lopez Uria Medardo	Mexico
Lifshitz Alberto	Mexico
Nava Diosdado Moises Rodrigo	Mexico
Serrano Zamago Ana	Mexico
Sueiras Altamirano Perla Ximena	Mexico

What can Clinical Bioethics Offer to Our Mexican Contemporary Reality?

De los Ríos Uriarte Ma. Elizabeth	Mexico
Hall Robert T	Mexico
Tarasco Martha	Mexico
Weingerz Mehl Samuel	Mexico

Ethics, Morality and Evolution

Bustillo-Ramírez Rodrigo	Mexico
García-Deister Vivette	Mexico
Rodríguez-Caso Juan Manuel	Mexico

Bioethics Education 2.0: Advancing Continuing Professional Development in Ethics for Healthcare Professionals

Chin Jacqueline J	Singapore
Berlinger Nancy	United States

Dunn Michael	United Kingdom
Moazam Farhat	Pakistan
Rodriguez-Arias David	Spain
Tsai Daniel Fu-Chang	Taiwan

Revision of the CIOMS Guidelines for Biomedical Research Involving Human Subjects

Bhan Anant	India
Macklin Ruth	United States
Rid Annette	United Kingdom
Van Der Graaf Rieke	Netherlands
Van Delden Hans	Netherlands

"Vulnerability" in Research Involving Human Participants

Campbell Alastair Vincent	Singapore
Ho Calvin Wai-Loon	Singapore
Saxena Abha	India
Shah Seema K	United States
Whittall Hugh	United Kingdom

Neuroética y droga. Estado penal y salud. Drogas de uso ritual, recreativo y de abuso

Linares Salgado Jorge Enrique	Mexico
Pellicer Graham Francisco	Mexico

Consent and Assent in Pediatric Research: Global Issues

Baines Paul	United Kingdom
Cheah Phaik Yeong	Thailand
Kelley Maureen	United States
Sheehan Mark	United Kingdom

Current Controversies in End-Of-Life Ethics

Bernheim Jan L	Belgium
Capron Alexander	United States

Holm Søren	United Kingdom
Raus Kasper	Belgium
Sterckx Sigrid	Belgium

Bioethics and Security of the Patient Wellbeing and Human Rights

Caballero Velarde Maria Cristina	Mexico
Mendoza Carrera Enrique	Mexico
Tarasco Martha	Mexico

Contemporary Ethical Challenges to Organ Transplantation in Asia

Arima Hitoshi	Japan
Chin Jacqueline J	Singapore
De Castro Leonardo Doloroso	Singapore
Lederman Zohar	Singapore
Lee Il Hak	Korea, Republic of
(South Korea)	
Tsai Daniel Fu-Chang	Taiwan

Bioethics and Indigenous Peoples: Public Health and Peace

Bagheri Alireza	Iran
Macer Darryl	Thailand
Rodriguez Alanis Martha Marcela	Mexico

Food Choices, Responsibility and Bioethics

Hunter David	Australia
Munthe Christian	Sweden
Verweji Marcel	Netherlands
Womack Catherine	United States

Acts and Omissions Across Bioethics

Ausín Txetxu	Spain
Rodríguez-Arias David	Spain

Téllez Elizabeth	Mexico
Triviño Rosana	Spain

Global Bioethics and Climate Change: Science, Society and Individuals in Latin America and the Caribbean

Altamirano-Bustamante Myriam	Mexico
Hariharan Seetharaman	Trinidad and Tobago
Macpherson Cheryl	Grenada
Philpott Sean M	United States

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The success obtained during the conduct of the 12th World Congress of Bioethics would not have been possible without the commitment and dedication of every one of the people that make up this great team. May this space as a recognition of colleagues and peers.

Maria de los Angeles Marina Adame Gayosso	José Manuel Lozoya Pacheco
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Angus Dawson, Manuel H Ruiz de Chávez, Mercedes Juan, Søren Holm and Guillermo Soberón.

Attendees at the opening ceremony.

Participants of the symposia: Integrity in medical research: urgent as it is.

The MH-Poster Prize runner-up team.

Opening ceremony

Alex Capron, José Ramón Cossío, Maria do Céu Patrão Neves and Ruth Faden.

The Library of Mexico, Cultural Activity venue.

See you in Edinburgh.

12th World Congress of Bioethics, Inspire The Future To Move The World
se terminó de imprimir en el mes de enero de 2015 en Edamsa Impresiones
S.A. de C.V., Av. Hidalgo 111, Col. Fracc. San Nicolás Tolentino C.P. 09850,
Iztapalapa, México D.F. Su tiraje fue de 1,000 ejemplares.

Commemorative sculpture by Yvonne Domenge on the occasion of the 12th World Congress of Bioethics held in June 2014 in Mexico City. The work consists of 50 numbered pieces. (photo by Michel Zabé)

Bioethics is a field in which numerous professionals and experts engage in an ongoing investigation into the proper duties of society and medical professionals to life. Centered largely on duties to human subjects in both research and clinical care, bioethics has been enlarging its domain for decades, encompassing now questions of duties to animals, ecosystems, and humanity in general. Because of its extensive reach, for its progressive growth we depend upon constant questioning, new ideas, and challenging cases. Given the rapid pace of technological and societal change, there is never any dearth of material to explore and every international conference and congresses like the one documented in this book offers an opportunity to learn, discuss, debate, and grow our discipline and collegial environment.

The World Congress documented herein was just such an instance, and we have attempted to capture as much of it as possible, including plenary sessions and other highlights over the course of four days in downtown Mexico City. Mexico's own recent commitment to engaging the public at large, and internationally, with bioethical issues served to foster many of the discussions and debates with which attendees grappled. As well, the experts, scholars, and practitioners who attended brought to the table experience, cases, and points of view that we hope will be of interest and benefit to anyone engaged with bioethics, either professionally or casually.

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